



# Genetics and Faith

**Power,  
Choice, and  
Responsibility**



**Evangelical Lutheran  
Church in America**

God's work. Our hands.

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## ***Genetics and Faith: Power, Choice, and Responsibility***

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## Letter from the Executive Director of the Program Unit for Church in Society

November 2008

Dear Partners in Mission and Ministry:

The ELCA program unit for Church in Society is pleased to make available *Genetics and Faith: Power, Choice, and Responsibility* as the first publication in the process of developing a social statement on genetics. You have in your hands an ambitious and solid set of Christian reflections that invites you to join in study, discernment, and deliberation. Your participation is vital as our church thinks together about these matters and faces the broad and pressing implications for our time.

The challenges of genetics are daunting but this study brings to life the stories and challenges faced by many, if not most of us today. These are stories about pastors and other church leaders and those who live their vocation in science, medicine, farming, business and a growing list of other occupations. These are stories about parents, teens, consumers, and aid workers. The study brings to light what is at stake for all of us as our human power to work with the genome expands rapidly. It presents faithful and thoughtful reflections that can teach and encourage discussion on questions related to congregational care, global realities, justice, and the common good.

On behalf of the Church in Society unit I want to thank the energetic and dedicated members of the ELCA Task Force on Genetics who have produced this engaging and comprehensive study. I know hours of loving labor have gone into their efforts to lead this church in the process toward a teaching and policy statement on genetics slated for consideration at the 2011 Churchwide Assembly.

It is my hope that many in this church will benefit from the task force's work by engaging it and will, in turn, aid them by providing many thoughtful responses. That deadline is November 1, 2009, and your response provides crucial input for the task force's thinking when they begin to craft the draft social statement that is due to be released in early 2010.

In Christ,



Rev. Dr. Rebecca Larson  
Executive Director  
Church in Society

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# Introduction to this Study Booklet

The science and technology of “genetics” is hard to miss today. News about it appears regularly, sometimes daily, in headlines announcing scientific breakthroughs, new applications, and moral quandaries. Many commentators talk about the 21st century as the age of genetics or biological control because our new knowledge grants human beings the power to change, at deep levels, the character of society and even the course of life on this planet.

While the positive potential of genetic knowledge is rightfully celebrated, its application presents challenges that range from curious novelty to troubling personal crises to social dilemmas. In such a time, many ask: “What does my church teach about these developments?” That kind of question led the 2005 ELCA Churchwide Assembly to authorize the development of a social statement that would address “significant theological, ethical, public, and pastoral challenges arising from developments in genetics.”

The task force charged with guiding the development of that statement has drawn upon previous work done by this church (see Additional Resources, below) and labored for two years to produce this tool for study and deliberation. The task force has come to believe that the nature of human power and the responsible application of that power for blessing or bane is the fundamental issue posed by the age of genetics. At the same time, the task force has discussed particular issues that are controversial in various sectors of our society, such as stem cells or the use of genetically engineered products.

This study is laid out in two parts in order to do justice to both fundamental challenges and particular concerns. Part A addresses fundamental social, theological and ethical themes, while the sessions of Part B engage particular scientific and biotechnological issues and topics in light of those themes. Both parts invite members of this church to faithful conversation, according to their particular interests and concerns.

That last point—according to interest and concern—is crucial to stress. Given the size and complexity of genetics as a social concern, the task force knows that most participants will only be able to study four to six sessions. Rather than attempt to prioritize which of the many crucial topics should be excluded, the task force conceived of this study as a smorgasbord. That is, it provides a variety of choices for group use and individual reflection and provides more food for thought than most will be able to ingest. They believe it is not necessary for participants to study every session in order to benefit from the material or to provide the response they seek from this church.

Each session is intended to be an entry point to the subject of genetics and, therefore, each session is reasonably self-contained. The study is designed with group discussion in mind, but is also suitable for individual reading and reflection. The task force welcomes responses from individuals who are not able to participate in group study but have worked through all or some of this material on their own. It should be stressed that the task force encourages *everyone who uses the study to take time to provide a response* using the form at the back of this study book. Those responses are vital to the task force’s ongoing work.

## ***Discernment, deliberation, and dwelling in the Word***

The first social statement adopted by the newly formed ELCA was titled *The Church in Society: A Lutheran Perspective*. It describes the church as “a community of moral deliberation.” Such a community can be defined as a context for and contributor to both personal and public morality. It stresses the responsibility of members of the church to engage together in thoughtful, well-informed deliberation about questions and problems that are theological and moral in nature. This study is designed to put this understanding of the church as a community of moral deliberation into practice.

This model underlines the fact that Christians of good will can and do disagree about moral questions, even though they share many basic values and convictions. Deliberation sometimes is difficult because social concerns like genetics are complex and have an institutional and structural pay-off, as well as a personal dimension. Still, it is the conviction of this church that moral deliberation should be conducted by “everyday folk” and not

## **Assembly Action CA05.06.25: Social Statement on Bioethical Research**

*(Adopted by the 2005  
Churchwide Assembly in  
Orlando, Florida.)*

Resolved: To receive with gratitude the memorial of the Northeastern Iowa Synod requesting that an ELCA social statement on genetic research and therapy be developed; To acknowledge that conversations on this topic already are being conducted throughout society and this church; To call upon the Division for Church in Society (or the appropriate churchwide unit) to develop a social statement that addresses significant theological, ethical, public, and pastoral challenges arising from developments in genetics in accord with ELCA guidelines (as set forth in “Policies and Procedures of the Evangelical Lutheran Church in America for Addressing Social Concerns”) for possible consideration by the 2011 Churchwide Assembly; and To encourage continued faithful conversations on this topic throughout this church during the study process.



simply specialists of whatever field. This model of being church together calls us to bring our Lutheran imagination and conviction to the task of communal moral deliberation.

To help us in our deliberation, the task force acknowledges the importance of dwelling in the Word of God in order to discern how God may be speaking to us individually and in our faith communities. A key feature of this study, therefore, is a selected reading from Scripture at the beginning of each study session so that dwelling in the Word may initiate the process of *discernment* that will lead to moral or theological *deliberation*.

### Action

Genetic science moves rapidly, and many who pick up this study may believe they simply don't understand the science well enough to discuss the issues. The task force sought a remedy for this problem, without burdening the study itself with extensive scientific explanations, by: (1) providing a primer on genetics and a glossary at the back of the study book, and (2) making available a DVD, *Cracking the Code of Life*, a NOVA series acclaimed for its lively and entertaining introduction to basic information about genetic advances. It is important to express thanks to WGBH in Boston for extending an educational discount to the ELCA so we can offer the DVD free upon request.

The fact of rapid scientific advance is a reminder that while the primary focus here is reflection, the ultimate purpose of our study is morally responsible action. The speed of change, the broad impact of new technologies, and the complex character of developments, mean that we cannot simply think our way to answers. Study and discernment will grant us new insights, clarity, and guidance. Yet the Christian responsibility encouraged in this study must be *lived into* with simultaneous measures of faith and courage, fear and trembling, joy and hope. The ways in which God's people deliberate in order to discern God's leading, and the ways in which Christians will give an account in this century to genetic developments, will shape an important witness to what Christianity actually is, and who Christ really is for us today. These are not armchair conversations.

## What is in the study

The following provides a summary of each session's content.

### Part A: A framework for conversation, prayer, and action

**A1 The Global Reach of Genetics** introduces the study of genetics from a faith perspective by focusing on the question "what is going on" in the world today? It describes how we are moving into an age of genetics that confronts us with unprecedented choices and daunting responsibilities. These choices and responsibilities often lead to profound disorientation and sharp controversy as we try to make wise decisions. This session suggests, also, that each of us has a personal responsibility in these developments, and it sketches some of the challenges—as well as bedrock commitments—for Christians living in these times.

**A2 Caring for Neighbors** explores how the study of genetics affects broad human self-understanding, and how Christians understand their God-given vocation. It explores the relation of humans to the rest of nature, and then reminds us of the global scope of genetic developments—developments experienced in a variety of ways by people in different parts of the global village. The session also discusses the problems of sin, failure, and human limitation. It concludes by charting the meaning of God's love that washes over us in our baptism, giving us profound vocational direction. This direction calls us to love, to careful thought, and to responsible action that seek to bring out the potential good of genetics while avoiding the potential harm.

**A3 Human Power Today** investigates the important question of what it means to be a human being in light of our relationship to God, and with an eye on how advances in genetics are interpreted in our society. The first section identifies some troubling ways of thinking about human beings related to what might be called "the gene myth." The second then sketches Christian ways to think about being human in relation to God, the

A complimentary copy of *Cracking the Code of Life* can be obtained either by calling the ELCA resources line at 800-638-3522 ext 2996 or by contacting Augsburg Fortress by phone or online. (800/328-4648 or [www.augsburgfortress.org](http://www.augsburgfortress.org))



creation, and to one another in the contemporary world.

**A4 Christian Responsibility Today** considers the moral or ethical resources that Christians can turn to as they ponder the developments and social issues with which genetics confronts society. The first segment explores Lutheran convictions about scripture as a resource for the moral life, while the second identifies values that all people of good will might claim as touchstones for living in the genetics age. The last segment concludes by looking at several relevant moral resources taken from established social teachings of the ELCA.

**A5 Toward a Lutheran Ethic** This session brings together insights from previous sessions and invites reflection on the nature of Lutheran ethics in the age of genetics. It first presents elements for a moral framework, and then invites the reader to exercise moral imagination and judgment in evaluating these principles by trying them on for size. It concludes with a reminder of the bed-rock of faith, life, and action—the gracious and justifying promise of God.

## **Part B: Exploring responsibilities and engaging issues**

**B1 Genetics and Congregations** encourages conversation on how congregations might address genetics or genetics technology issues today. We must be prepared to understand enough of the science and to listen to the potential implications posed by genetics and biotechnology in order to consider how we, as Christians, might respond to the questions. Within congregations are families affected by the chronic nature of genetic conditions, people living in the midst of biotechnology they had no idea would impact their lives, and people called to advocacy for change because of their belief that in God's world life should be different.

**B2 Genetics and Human Identity** reflects on the issue of genetics and human identity and takes up the issue of genetic determinism. The session addresses questions such as: As Christians, should we consider our genome to be our essence? Is the answer to “who we are” found in the genome? Do our genes lead us to sin? Can God's grace work through gene expression? Can we reduce the most sublime of our intuitions to gene expression?

**B3 Genetics and Social Location** asks you to reflect upon the significance of social location for assessing the ethical dimensions of genetic research and treatments. The focus will be upon communities of color and women of color. You will be asked to reflect upon your own social location and how it has shaped your ethical worldview.

**B4 Genetic Testing and Screening** invites you to learn more about genetic testing and screening and to reflect about the personal challenges it presents. Three examples are provided from real life situations: cancer genetics, prenatal testing, or teens at risk. The first section of reflection describes vital background about each example. The subsequent section provides key ideas about each in relation to faith. Readers are then invited to reflect at length on one of these examples as a way to explore its personal challenge.

**B5 Genetic Engineering in Agriculture** considers concerns around the use of genetically engineered crops, animals, and microbes in agriculture. Scientists, farmers, agribusiness representatives, activists, policy makers, and food eaters hold a variety of different, complex, and even mixed perspectives on how to promote the promising aspects and prevent the perilous ones. Activists on competing sides of the issues produce strongly worded position statements that may help to inform the dialogue, but may also serve to mislead and misinform. To promote debate and discernment, this session introduces some of the key issues that shape people's perspectives on the promises, perils, and controversies.

**B6 Stem Cell Research and Therapy** offers an overview of the state of stem cell research today, and identifies the key ethical issues in the debate in order to facilitate engagement with stem cell issues. By exploring these issues from a variety of perspectives, the reader will gain a deeper understanding of what is at stake in this controversy. The session hopes to aid each reader to understand why he or she holds his or her views and why equally informed, conscientious Christians may make different judgments.

**B7 Patenting Genes** considers the complex matter of patenting genetic inventions or discoveries. It connects this issue to the biblical idea of blessing and curse, and asks how such patents could be blessings or curses, and for whom. The session first covers the contemporary significance of gene patents, how genes came to be patented, and the advantages and disadvantages of genetic patents. It then widens the focus to discuss genetic patents in terms of developing countries and international trade. The final set of reflections raises some biblical themes that can help us consider ethical issues in the use of gene patents and in patent laws and regulations.

**B8 Enhancing Human Life** explores questions of faith and witness around the use of genetic knowledge and technology to “enhance” life. Christians claim a calling to care for the disabled and to heal disease. As disciples of Jesus, we seek to restore wholeness to the brokenness of life. But suppose that new powers over mind and body, today and in the future, allow us to be “better than well” in the sense of improving upon the genetic inheritance that we receive from God through biological parents. Is this a new calling for people and society or not? If so, what should this mean practically? If we can make people better, do we owe this to future generations?

### *Additional resources*

The following publications represent work in which the ELCA's churchwide office has been directly involved. The purpose of each has been to encourage conversation and moral deliberation. As such these remain the work of individual writers and are not official statements of this church even though they are recommended resources.

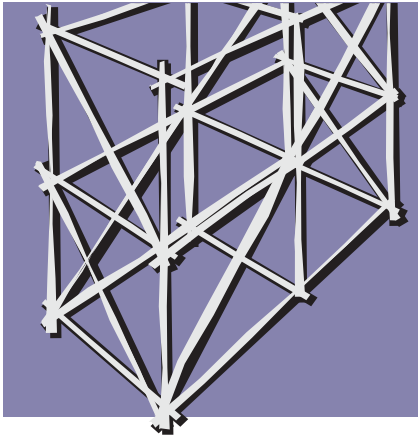
David C. Ratke, *Theological Foundations in an Age of Biological Intervention*. (Minneapolis: Lutheran University Press, 2007).

*Genetics! Where Do We Stand As Christians?* (Chicago: Division for Church in Society, 2001).

Roger A. Willer, *Human Cloning: Papers from a Church Consultation*. (Chicago: Division for Church in Society, ELCA, 2001).

Roger A. Willer, *Genetic Testing and Screening: Critical Engagement at the Intersection of Faith and Science*. (Minneapolis: Kirk House Publishers, 1998).

# Part A: A Framework for Conversation, Prayer, and Action





# The Global Reach of Genetics: Unprecedented powers and choices

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

Lord God, you have called us to ventures of which we cannot see the ending, by paths as yet not traveled and through challenges and perils as yet unknown. Give us faith to go forward with good courage, not knowing what the future holds but confident that the future is in your hands. By your grace lead us and with your love support us, through Jesus Christ our Lord. Amen.

(Lutheran Book of Worship Occasional Services, p. 245)



### HEARING THE WORD

Ecclesiastes 3:1-8

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God here for us?

## Introduction

### Session summary

This first session introduces the study of genetics from a faith perspective by focusing on the question “what is going on” in the world today. It describes how we are moving into an age of genetics that confronts us with unprecedented choices and daunting responsibilities. These choices and responsibilities often lead to profound disorientation and sharp controversy as we try to make wise decisions. This session suggests, also, that all of us have a personal responsibility in these developments, and it sketches some of the challenges—as well as the resources—for Christians living in these times.



### Real life stories

Today Genetics is...  
As common as chocolate.

“To save chocolate lovers from the agony of a potential candy bar shortage, McLean candy giant Mars® is investing \$10 million in a five-year project to develop cacao trees that fight drought, disease and poor harvests.

“Mars will announce today that it is partnering with IBM and the Department of Agriculture to sequence and analyze the entire cocoa genome. The team...plans to breed the genetically superior specimens to battle the foes that have shrunk the number of beans to make chocolate over the years.

“We have the ability as a private company to take charge of the future,” Howard-Yana Shapiro, global director of plant science for Mars, said.

“Unlocking the secrets of the genome and eliminating the guesswork in traditional breeding could bring economic stability to the 6.5 million small family cocoa farmers around the world and help fend off the environmental assaults that inflict \$700 million to \$800 million in damages to farmers each year,” Shapiro said.<sup>1</sup>



Ecclesiastes’ wisdom is that different times require different insights and different skills, whether we choose the time or the time chooses us.

What is the time and purpose of your life right now?

Genetics in its narrowest sense simply refers to the study of biological heredity and the role of genetic material in the functioning of life. *Genetics*, as used in its broadest sense in this study, however, serves as a catch phrase for the collective developments, implications, and impacts of genetically informed knowledge and technology. The *science of genetics* will be indicated as such.

## As complex as DNA itself

Watch *Cracking the Code of Life*, Segment 1: Instructions for a Human Being.

(Note: This NOVA program from public broadcasting introduces the science and technology of genetics by exploring the Human Genome Project (HGP), the huge scientific program to “decode” the basics of the human genome. The HGP is in many ways the symbol of the age of genetics.)

## As global as food

In 1999, Larry Proctor, a Colorado businessman and farmer, was awarded U.S. Patent Number 5,894,079 for Enola beans. The Enola bean plants produce nutritious yellow beans. Proctor’s patent application claimed that he had developed this new variety of bean plant from another variety he purchased in a Mexican market. Proctor’s patent entitled him to 20 years exclusive control over the Enola beans and any hybrids grown from crossing other beans with just one Enola seed. After receiving his patent, Proctor enforced it aggressively against planting, selling, or exporting the beans without a license from him, claiming 60 cents on every pound of yellow beans sold in the United States. His actions resulted in a significant reduction in exports of yellow beans from Mexico to the U.S. These imports served a market for yellow beans created by immigrants from northwestern Mexico where yellow beans were commonly grown and consumed.

In April, 2008, however, the U.S. Patent and Trade Office revoked Proctor’s patent after a patent reexamination and appeal process. The review was initiated by the International Center for Tropical Agriculture (CIAT) of Colombia, which maintains a crop gene bank. CIAT showed that Enola beans were neither new nor was their development “non-obvious.” Rather, it said that they are indistinguishable genetically and by color from at least six varieties of yellow beans, known commonly in Latin America as *azufrado* or Mayocoba beans, in their collection. These beans, it claimed, had been grown there for generations and had been part of the diet of Latin Americans for over a century. It also demonstrated that there was published scientific literature about the beans. A scientific team unrelated to the patent reexamination independently concluded that the DNA of Enola beans is identical to a variety of Mexican yellow bean known as Azufrado Peruano 87 from which they were most likely directly derived. Proctor may still appeal the patent revocation to the Federal courts and possibly to the U.S. Supreme Court.<sup>2</sup>

## As personal as whether you would choose to live to 280.

In addition to reducing and removing the incidence of disease through gene therapy, some think medicine should seek to alter individual human genomes so that we can be better than healthy, in a word, “enhanced.” In one vision of this future, perhaps 100 years from now, humans will have techniques that will allow them to add modules of genes for preferred characteristics by adding artificial, auxiliary chromosomes into our present 46. These modules could override or “knock out” certain genes we do not want to be expressed, and add or “knock in” certain genes we want to improve our lives. Like computer software that gets upgraded, parents might choose not to pass on the artificial chromosomes that they received from their parents. They could instead use the latest version of auxiliary chromosomes for their child, which might protect better against cancer or increase toleration for heat.

Some genetic research today is creating a pathway to such genetic intervention. Suppose that this technology could allow people to experience life more richly, to understand it more deeply, to create better, to cooperate well, and to undertake all sorts of other human endeavors more competently, and to be more of what people long to be. Should people use genetic technology to pursue this goal? People like Michael West think so. He is a scientist and entrepreneur who has achieved remarkable success as a kind of merchant of immortality. He founded a company in 1990, dedicated to studying the molecular causes of aging, named *Geron*, Greek for “old person.” West and Geron speak tirelessly of “immortalizing enzymes” and the “life extension of cells...”

## The Age of genetics

Do you remember what it was like to start high school? Remember how exciting, nerve-wracking, awesome, and unfamiliar it was, all at the same time? Do you remember the challenge of finding your way through strange hallways, making the locker work, figuring out how to get out of gym on time, dealing with many new people and with what seemed like even more new expectations? No matter how well you made the transition, you had challenges and you knew life would never be the same. This experience inevitably raised a very basic question: Who am I going to be in this new school? Transitions always require us to figure out our identity all over again.

Transitions like this are as old as the human race itself, as is evident in the stories of God's people in scripture. In fact, scripture is one story after another of people being lead, urged, even pursued for the sake of new vocations in new times and places. (Jonah 1:1–3:3) Abram and Sarai are called to move from Haran to Canaan. (Genesis 12:1–9) God forms a new people by leading Moses and the Israelites out of Egypt through the tumultuous Red (or Reed) Sea. (Exodus 12:1–15:21) In the desert, the Israelites anxiously grumble about how they are going to be fed during the transition. (Exodus 16:1–17:7) God calls them into a new relationship through the giving of the Ten Commandments, which gives them laws for honoring God and their neighbors on the way. (Exodus 12:1–17) On the edge of the Promised Land, the Israelites must begin to figure out how to put into practice the laws that were given for this new time and place. (Joshua 1:1–10)

In the New Testament, God through an angel commands Joseph to take his family and flee to Egypt to avoid Herod the King. God also tells Joseph when it is time to return to. (Matthew 2:13–23) Jesus himself travels throughout Galilee up to its traditional borders with Syria and Phoenicia for the sake of his mission to preach the good news. (Mark 1:14–7:30 for instance) Once risen, Jesus commands the disciples to become apostles: those sent to the ends of the earth. (Acts 1:6–8) Each of these stories teaches that God is present in the midst of life's transitions and that each new time and place is sacred in the sense that God is already there—no matter what the troubles, failures, disorientation or new identity that God's people experience.

American society, and most of the globe, is now in transition. We are moving into what should be thought of as a new “place” or a new “age,” the age of genetics. It too is exciting and daunting, full of potential and worries. However, whatever else it will mean, “life will never be the same.” Just as the industrial and the information ages brought sweeping changes, so will the genetic age. In fact, the changes may be even more significant because of the different kind of power they place in human hands, and the extent of that power on all living things. It is already clear that the advance of genetics will alter in some way every aspect of life and every society across the globe. Those effects range from the way corn or chocolate is grown to the way medicine is practiced to the possibility of creating artificial life. They include the creation of whole new industries that respond to the ailments and misfortunes of life, and raise the possibility that humans could live three times as long as they do now. This new age also affects *all life* on earth in unprecedented ways since it involves the direct engineering of the biological code and related processes that are fundamental to life. Moreover, these changes will help reshape human self-identity, if for no other reason than that they show us how interdependent humans are with one another and with the rest of nature.

The transition into the age of genetics is certainly one of the more exciting, yet unsettling and daunting, changes human society has ever faced. It is understandable to wish it were simpler and less complex. The truth is, though, that for better or worse, our society, indeed the human race, is going to be living in the age of genetics for good. We must take responsibility for this new living space because it's not going away. Individual and collective decisions must be made, regulations must be developed, and profound questions about how to shape both nature and the human future must be faced. Some of the questions for Christians include: How then shall we live in a society increasingly driven by bioengineering? What perspective does our faith grant us on these developments? What are the givens? In what ways do we have power and choice? What do we think God's

This new era has many different names in the literature and media about it. These include: the age of biological manipulation, the genetic engineering era, and the age of biotechnology among others. Each of these terms highlights certain aspects of the unprecedented powers and choices that the science and technology of genetics includes. This study will use the summary phrase *age of genetics* most often but will employ alternate terms as appropriate.



Many specialists worry that we have only a 10-to-20-year window in which to build the legal and regulatory structures necessary to channel this new genetic knowledge, and its technology, in directions that will encourage healing and genuine human flourishing rather than lead to Huxley's nightmare.

intentions are in all of this? What should this church, and we as members of it, be saying both in the public debates and about the decisions that need to be made?

Fortunately, God's people can humbly yet courageously face these questions and live in this new age. This is possible because of some of the "givens" we bring with us as people of faith. Foremost among these "givens" is the assurance of God's presence and goodness. We can be sure that God is active in this transition and that it is therefore one in which God's people are called to be faithful and responsible. Yes, there are problems to be faced, harms to be avoided, and perils to be recognized. But this new age also offers the opportunity to multiply benefits, learn more about our God, and appreciate anew our God-given inheritance. It is a new chance to be faithful in caring for the neighbor and a new "place" where we are called to learn more about ourselves as we discern what God is doing and calling us to do.

In addition we should not forget that we move into this new era with "other students." The knowledge, power, and changes afoot involve other people at both the local and global level who are Christian brothers and sisters. It also involves others of different faiths or even of no faith who, Christians believe, can serve as God's hands in the world too. This move into the age of genetics involves many different actors through whom God would work for the good of all, and for whom there is a crucial stake in how our civilization settles into the genetics era. Finally, we can walk confidently into this new age because there are resources from the inheritance of faith that we carry with us.

## Resources for faithful engagement

### *Christian commitments*

1. Christians claim that Christian faith provides a framework story within which all human and non-human experience unfolds. The story of God's creation, redemption, and consummation (God's intended fulfillment of creation) provides the most basic framework of meaning for the human enterprise (and for the whole universe itself for that matter!). This overarching framework can help us integrate the new experiences and identities we need in the age of genetics because, while this framework includes the universe, it is at the same time as personal as God's love shown in Christ for each human, molecule, and particle.

The center of the story is Jesus Christ, "who, though he was in the form of God, did not regard equality with God as something to be exploited, but emptied himself, taking the form of a slave (to God) being born in human likeness." (Philippians 2:6-7) Jesus Christ is also the one "in whom all things in heaven and on earth were created, things visible, and invisible, whether thrones or dominions or rulers or powers—all things have been created through him and for him." (Colossians 1:15-20) He is, on the one hand, the model of the form that human nature should take. He is on the other, the one in whom all alienation, tragedy, and guilt is overcome. This Christian story firmly recognizes human beings as natural creatures who yet have accountability for their actions before God in relation to one another and all of nature.

2. Christian faith can speak of the goodness of genetics as part of God's creation in the highest terms. This follows from understanding God as the creator who affirms the handiwork of nature through the incarnation of Christ (Jesus had 46 chromosomes too!) by raising Jesus from the dead. Christians claim that God's work in the cross and the resurrection of Jesus is a down payment on God's promise to bring creation to fulfillment (Romans 8:21). Thus, humans can celebrate being part of the creation into which genetic knowledge gives us insights.

3. Christians affirm that nature belongs to something greater than human design and that the human race is accountable to this greatness—to the God we know in Jesus Christ. To know that the infinite God is active in finite nature is, therefore, to have a resource to critique the sometimes subtle but overweening pride when biotechnology is offered as the solution to a set of problems. Christian faith, then, will not tolerate any intervention into nature that looks upon creation as a personal belonging or believes that humans may do

whatever they want with it. Christians call this sin and recognize that it is present in all personal and structural dimensions of life.

4. This suggests that Christians should see genetic developments in our lifetime as a life space in which to meet God and discover new meanings of Christian faith. This includes recognizing God's work in the huge social and economic forces at work, while yet calling each individual to personal responsibility. It also includes recognizing that God dwells with us in such everyday places as the medical office or the biotech boardroom, etc. The age of genetics involves global-sized corporations and decision makers, hungry people, doctors and patients, international trade agreements, government policy, insurance companies, farmers, entrepreneurs, and on and on. All of these "actors," along with each individual, have a role in determining what the living space of the age of genetics will look like. A key challenge is to avoid idolizing human power while knowing that God acts through and is active in such real world places.

5. A critical commitment among Christians is to use the resources given to us by our heritage of faith. The most fundamental written resource is, of course, Holy Scripture through which God communicates. Lutherans look also to their Confessions as a faithful interpretation of the Bible and they value their heritage of theological reflection. One particular expression of faith's intersection with contemporary thought is found in the ELCA's social statements. These social statements will be important because they indicate established points on many particular matters affecting genetics, like economic life, health care, human responsibilities for creation, and more.

The Lutheran heritage of faith also affirms drawing from what it has typically called "sound reason" or what could be called *common knowledge*. It includes good logic, scientific knowledge, civil law, business practices, and more. Lutherans understand that there are no guarantees that Christians will think more clearly than others about the science of genetics and matters of public policy. Therefore, we affirm all such knowledge and wisdom that encourages the good of the neighbor and does not make false claims about God.

### **Critical engagement**

The approach suggested by these commitments could be called one of *critical engagement*. Critical engagement follows from, for instance, the conviction that genetic developments are to be understood as occasions in which God is engaged as creator, redeemer, and sanctifier to bring about the good. God is engaged and calls God's people to be also. Gratitude and religious concern are the starting points. This involves a critical tension, quite clearly, given the Christian recognition that sin is just as assuredly present in this human enterprise. God is engaged to protect from harm and evil and so God's people must be *critically* engaged. Overweening pride and the misuse of power and knowledge is prevalent in genetics, as in all human activity. Mindful of this, and because God encounters us precisely in such ambiguous situations, we are called to be attentive to God's activity and will.

Critical engagement means, also, that the only satisfactory way to approach genetics is by engaging the scientific, medical, and economic knowledge involved. This idea assumes that legitimate two-way connections exist between everyday life and the religious language of faith—that is, between "Monday" and "Sunday." Further it holds that Christians *must* address genetic issues and do so deliberately. Neither uninformed rejection nor complacent acceptance is an adequate response.

Critical engagement, finally, signifies that the developing genetic knowledge and its application are to be affirmed in principal as means to aid human endeavors for healing, the alleviation of suffering, and so forth. At the same time, it holds that people of faith must critically consider each specific development according to judgments informed by Christian resources such as scripture. Does this use of genetics really serve the good of the neighbor? Do these decisions lead to justice? Christians sometimes will resist a particular employment of genetic knowledge and technology while accepting its use in other ways.

*Common knowledge* is common in the sense that it is not specific to our religious experience or faith. Such knowledge may be contested, of course, as in the case of laws or available primarily to experts as in the case of scientific technology. Still, in theory it can be understood by the general public regardless of their faith beliefs.

## Invitation to conversation, prayer, and action



### QUESTIONS FOR DISCUSSION

- Share your memories about going to high school. What was it like? What were some of the “givens?” What were some of the choices that had to be made? What excited you? What was difficult? How did it change who you were? How did it not?
- How has your life been affected by the advance of genetic knowledge? Share an illustration of that. What worries you about the huge impact of genetics on society? What excites you about it? What do you find challenging?
- What Christian resources do you think Christians bring with them into this age of genetics? How will they help you make decisions?
- Action question: Name two specific personal or public issues that must be considered regarding the use of genetic knowledge and technology. Have you (or could you) accept responsibility for dealing with one of them? In what ways? Does your congregation have any responsibility to respond to matters related to genetics? What actions could you, your congregation, or your civic leaders be encouraged to take?

### *Closing prayers*

#### INVITATION TO INTERCESSORY PRAYER

Pray for those who anxiously stand at the “thresholds” of life uncertain of what the future holds, and pray for those who serve as teachers, mentors, and spiritual guides.

#### PRAYING WITH THE TRADITION

O Living God, to turn away from you is to fail, to turn toward you is to rise, and to stand before you is to abide forever. Grant us, dear God, in all our duties, your help; in all our uncertainties, your guidance; in all our dangers, your protection; and in all our sorrows, your peace, through Jesus Christ our Lord. Amen.

(Prayer of Augustine of Hippo, who lived 354-430)

### *Endnotes*

1 Kendra Marr; Washington Post Staff Writer; Thursday, June 26, 2008  
[www.washingtonpost.com/wp-dyn/content/article/2008/06/25/AR2008062503374.html](http://www.washingtonpost.com/wp-dyn/content/article/2008/06/25/AR2008062503374.html)

2 For more on this incident see “USPTO rejects patent protection for yellow bean,” *BioSpectrum—Asia Edition*, May 5, 2008 ([www.biospectrumasia.com/content/050508oth6144.asp](http://www.biospectrumasia.com/content/050508oth6144.asp), accessed September 16, 2008).

# Caring for Neighbors: Vocation, responsibility and community

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

Almighty and Eternal God, so draw our hearts to you, so guide our minds, so fill our imaginations, so control our wills that we may be wholly yours, utterly dedicated to you. Then, we pray, use us to your glory and the welfare of your people, through our Lord and Savior, Jesus Christ. Amen.

(*Evangelical Lutheran Worship*, p. 86)



### HEARING THE WORD

Genesis 1:1-31

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

This session explores how the study of genetics affects broad human self-understanding, and how Christians understand their God-given vocation. It explores the relation of humans to the rest of nature, and then reminds us about the global scope of genetic developments—developments experienced in a variety of ways by people in different parts of the global village. It also discusses the problems of sin, failure, and human limitation. It concludes by charting the meaning of God’s love that washes over us in our baptism, giving us profound vocational direction. This direction calls us to love and responsibility that seeks to bring out the potential good of genetics rather than the potential harm.



### Real life stories

1. At the August 2005 ELCA Churchwide Assembly, Bishop Steven Ullestad of the Northeastern Iowa Synod introduced a request for the ELCA to create a social statement on genetics by telling the story of a microbiologist from his synod.

Ullestad remarked that this Lutheran biologist once told him: “Bishop, I have prayed every night for three years: God, why have you allowed me to see what I see each day but you have given me nowhere to talk about the implications of my work for the world and my faith?” Ullestad then went on to say, “As the conversation continued it became clear to me that in his work he was worried about doing good for all people and caring for creation. He was concerned that his research not serve human arrogance or just economic gain. I also realized that he represented many, many in our congregations whose lives as scientists, farmers, and parents intersect with this knowledge and power. “I pray,” concluded Ullestad, “that this church will take up the challenge, difficult as it is, to speak humbly but clearly on these matters.”

2. *Cracking the Code of Life*, Segment 1: Instructions for a Human Being (Begin at: minute 4:10 and run to 10:06)



The word “rule” used of the sun and the moon in v.16 and the word “dominion” used of men and women in v.28 have the same meaning: to regulate or order their divinely assigned sphere of influence.

What kind of interrelations are there among the plants, trees, creatures of the earth, the seas, and the air?

## The big picture

In the previous session we noted that the age of genetics raises the question of identity and is global in its impact. We could call these “big picture factors.” We begin, then, thinking about what genetics means for the broad topic of human self-understanding. What do genetic developments reveal about human identity and the nature of life in the twenty-first century?

### Humans as nature and their role as shapers of nature

The work of the Human Genome Project (HGP) symbolizes scientific efforts of recent decades that have shown how our human species emerged within the unfolding of a vast, huge, and ancient system that science calls “nature.” Christians, as a statement of faith, understand nature as God’s creation and, therefore, as good. The knowledge gained from genetic science helps make clear that humans are thoroughly dependent upon the processes that shape the rest of nature. Nucleotide sequences (DNA) should not be understood as mechanical, but they are clearly the physical foundation upon which our being human depends both for its constitution and its development. The nucleotide sequencing that the HGP has “mapped” undergirds everything from the cell structure of the simplest organism to basic personality temperament. It has even been demonstrated that we share 99.5% of our genes with the chimpanzee and other primates. Humans are nature!

Humans, like the rest of nature, should not be “reduced” to these sequences or processes. Moreover, humans have some unique genes and unprecedented characteristics compared to the rest of nature. Still, these sequences and the history embedded in the genetic code demonstrate that humans have undergone the same processes of generation, diversity, and selection as the rest of nature. The complexity of these sequences and processes is astounding scientists as they learn how complex the symphony of interaction with both other genes and the social environment is. As Christians, we also understand that all of this comes forth by God’s creative Word. Yet that point only enhances the recognition that humans *are* nature, created within the same web of life. (Psalm 104:1-35).

The fact that humans are part of God’s great enterprise called creation is related to the idea, suggested in the previous session, that humans have emerged within nature to care for it and help shape it. This is evident in many ways. Dogs, for example, exist only because of human intervention. Wolves, coyotes, and fox would exist if the human race did not, but dogs exist only because humans have bred them, beginning with those canine relatives, over long periods of time. Contemporary society as we know it, with nuclear power, artificial lakes, artificial physical elements, climate change, and biotechnology evidences the immense power of humans to shape nature. Human efforts—technology in this general sense—represent an ongoing outgrowth of and development of God’s creation.

This human shaping of nature can be captured by the term “technology.” We tend to think of technology as the computer screen in front of us or the souped-up engine roaring down the street, but technology is far more than just the things humans create. Technology is the use of the mechanical arts and applied sciences to fulfill “a desire and disposition rationally to understand, order, predict, and (ultimately) control the events and workings of nature all pursued for the sake of human benefit.”<sup>1</sup>

Given the immense power of today’s technology, it is important to realize that civilization is an outgrowth of nature’s unfolding. At the same time, particularly in the last century, it has become true that there is no aspect of nature that is not affected, fundamentally, by human civilization. All of this has become possible through the immense capacity of the human imagination coupled with the global power of technology.

The science and technology of genetics continues along this historic path of human development and is now shaping the earthly creation in unprecedented ways. There are many examples of this, but germ line engineering is one of the most common illustrations. In this process, researchers directly engineer sequences of DNA in germ line cells, cells like a fertilized egg, which means these changes will be passed down to future offspring. In this sense, it changes the basic genetic “code” of life. Breeding practices of the

Human Genome Project (HGP): an international research effort (led in the United States by the National Institutes of Health and the Department of Energy) to sequence the base pairs, identify the genes, and understand the human genome. The initial goal for this work was completed in 2000.



past created change in the “code” over years of trial and error, but germ line engineering directly alters it in one action.

Most people know about this from reports about genetically engineered plants such as corn or soybeans. (Many more organisms have been or will be engineered.) The point here is that the modification made to the DNA of those seeds is direct, immediate, irreversible, and will be present in all subsequent generations. Or to use common examples, the nature of engineered corn or soy has now been shaped differently by humans. Scientists predict that it will be possible to alter some aspects of the human germ line within the next 20 years or so. Humans are becoming shapers of human nature as well.

### The global realities of genetics

This shaping of nature does not happen in a vacuum; it takes place within complex sets of social and economic forces. This reality is often described as the “global village,” and it has great significance for developments in genetic science.

The image of the global village suggests three realities. The first is easily understood and commonly recognized: all people on earth are becoming ever more closely connected. The decision whether to use genetically modified seed affects not only what is in U.S. breakfast cereal but also what kind of seeds are available for African farmers. Or, in another example, oil prices, weather-related factors, and the robust U.S. demand for ethanol created new levels of hunger and new political instabilities in places like Haiti and Bangladesh, places already struggling with poverty and hunger. We live in a complicated global village, and decisions made in one part of the village, like ripples spreading across a lake, affect the whole village.

However, the image of the global village points to more than close connections. We who live in the United States often find it difficult to stay attuned to what others in the global village are experiencing. This is particularly true with respect to genetics where other peoples’ experience is often quite different from our own. Many in the global village do not have, and likely will not have, access to the fruits of genetic research, and decisions in the developed countries to focus on genetic research may have a negative impact on their basic needs. Many developing countries have crucial needs that do not require genetic solutions. Their needs have to do with issues of infrastructure, better food distribution, clean water, adequate housing, and medicine delivery for malaria, TB, or HIV-AIDS. Voices from some of these countries speak out against genetic research and development because it diverts attention and research from basic needs, primarily because its potential for profit is greater. While this negative experience and the factors involved cannot be adequately addressed in a few sentences, we need to at least be aware of the issues—they are important within the global village.

The third and related reality in the global village is that many of the decisions that affect everyone are often made by a relatively small number of individuals. Decisions, including what to research and where to direct the attention of science, are made in the interplay of many actors and forces, but key decisions are driven by a relatively small group of scientists, managers, and administrators in governments, industries, and universities. Moreover, their decisions are often directed to a specific interest group and focused on enhancing profits and advancing careers. What may get only secondary consideration is the common good and outcomes that may have profound impacts on multitudes of people.

The hidden power of small networks of decision makers is often overlooked, but it takes on concrete reality in the lives of multitudes both here and abroad:

- the newly married man, worried about keeping his health insurance if a certain genetic marker is found indicating susceptibility to colon cancer;
- the consumer wondering if family allergies will be affected by unlabeled food;
- farmers in Africa who may want to try engineered seeds, but who cannot afford to pay for them year after year as required by seed companies. (In the past these farmers have saved seed back after the harvest.)

*Social Location* refers to the idea that human beings are “located” in many social relationships and identities that shape their self-understanding, values and aspirations, and their perceptions of others and the world. Examples of these relationships include race/ethnicity; socio-economic class; gender; religious affiliation; mental/physical abilities; and age.

- family members of those with Parkinson’s disease who hope that genetic research will find a cure that will end or slow the disease;
- small business persons and local farmers in Mexico who have had to go to court to retain access to generations-old yellow beans (a particular variety of bean for which a company claimed they had a patent. (See session A1: Real life stories).

Each of these situations concretely demonstrates that human beings as a species are shapers of nature. Each also demonstrates that every day decisions related to genetics are made within the context of social and economic forces beyond the immediate control of most individuals. It is within this context, or “place” that our individual and social responsibilities play out today.

## More Christian resources

Given what we are learning about human beings and the nature of our global village, what additional Christian resources help form the basis of Christian self-understanding and analysis for living in these times?

### Christian vocation

Christian self-identity and reflection about life begin, always, with what God has done in Christ. The first session reminded us of this by framing the big picture of God’s creative, redemptive, and sanctifying work. That work becomes personal for each of us in our baptism and is constantly renewed through our lives in the church, the community of Word and Sacrament. The broad story of God’s love is specifically applied to *each* of us, if you will, in the Christian community when we are baptized. This sacrament of Word and water submerges the baptized in the work of God through Jesus Christ’s, life, death, and resurrection and jumpstarts each Christian’s vocation.

Christian vocation is a word frequently misunderstood. Many think that only those who are pastors or rostered leaders have a Christian vocation. But Lutherans understand that vocation is “a calling from God that encompasses all of life for all the faithful.”<sup>2</sup> It involves God’s saving call to each of us to live a vocation, a life, in joyful response to God’s love. In gratitude to God *the* single Christian vocation for each and every baptized person is to serve God in everything that we do. We understand from scripture that God’s desire is that we love the neighbor, seek justice, and promote the common good. For this we are called by God and accountable.

The single Christian vocation, then, is lived out in a variety of *callings*. It is lived out in the various role and “places” of responsibility each Christian finds him or herself. Each Christian’s callings are particular to the skills, education, *social location*, special roles, and other such factors particular to that individual’s life. In addition to particular callings, like our job or parenthood, all of us are called to *general* responsibilities such as being wise consumers, involved citizens, or good global neighbors. Each role brings with it appropriate tasks and practices that we are to fulfill. Each of these roles has “best practices and structures of responsibilities” that guide us in service to the neighbor, and there is great variety in these. Examples of such callings in relation to genetics include:

- biotech scientist
- parent who has to decide which genetic test or therapies to use
- genetics counselor
- farmer who must decide whether to purchase transgenic (genetically engineered) seeds
- member of watchdog organizations that challenge particular uses of genetic knowledge as unwise or unjust
- financial officer of a biotech firm
- legislator



Some of these roles may bring individuals into conflict at times, but God needs each one and each should be engaged in with prayerful discernment. In each case, the Christian vocation is to live out his or her callings in ways that bless God and serve the neighbor in the actions taken.

## Recognizing sin

As noted in session A1, the need for a critical analysis of the use of genetics follows from the reality of sin about which the Christian story is clear-eyed. Our faith insists we recognize the depth of sin that haunts all human activity, including genetic developments. Sin is sometimes thought of as a list of “don’ts and dos,” but the Lutheran understanding considers sin in broader terms. Sin describes the brokenness of our world, both personal and social.

In Luther’s discussion of the First Commandment in the Large Catechism, this brokenness is discussed fundamentally as a matter of our trust orientation to God. Sin is trust in self or in all “the wrong places” rather than in God. Sin manifests itself in various ways. Sin is being “curved in on one’s self.” That is, it is being self-focused at the expense of being in right relationship with God or neighbor, which is idolatry. Sin also describes our condition of ignoring God’s calling to service and love because of our bondage to fears, ambitions, and anxiety. It is crucial to recognize that sin describes more than personal or individual actions since it includes social and structural realities. Collective beliefs, practices, systems and institutions are also tainted by the brokenness named sin. The challenge here is to recognize that all kinds of human efforts are tainted by sin.

Such talk may seem theoretical but it has practical implications. Christian analysis, for instance, argues that the deepest challenge in the age of genetics is not the dilemmas associated with the study of genetics per se, but rather the radical extension of human power over nature and the ways that power can be exercised in sinful ways. In other words, Christian faith hones in on the deepest cause of potential harm—the moral fault or the sin—that infects this exercise of power. This analysis reveals pointedly the dangers of human power exercised in a society shaped primarily by an ethics of self-fulfillment in which power increasingly becomes an end in itself. Such Christian analysis insists that these insights must influence how we carry out our human responsibility in the age of genetics, as well.

## Ambiguity and confidence

While Christian faith recognizes the dangers of sin and thus gives an edge to critical evaluation, it does not negate the worth of human effort. In fact, it recognizes that good and sin are often mixed together in this life. No matter how full of sin and vulnerability they may be, human efforts do make a difference! Christian faith, then, continues to see genetic developments as part of God’s creative work, even if we cannot be sure how God will use our sin-tainted efforts. This too is the promise learned in the cross of Jesus—that God can use human sin for good. Even as Christian faith subjects human pride to critique, it equally motivates Christians to lives that move beyond inaction to seek healing and justice.

The Christian story also provides a benchmark for living amidst such ambiguity. The fullness of life revealed in Jesus Christ teaches us that all human action, including the development of genetic products and processes, should be congruent with *his* purpose. That is, the purpose of human life is self-giving for the benefit of creation and its people. This tenet from faith begins to provide Christians with the kind of questions we must use to evaluate genetic developments and determine the roles we will take. For instance: will this technology or marketing or service fulfill the common good of society or will its impact be limited or harmful? It also compels Christians to ask, about genetic developments and their delivery: who makes those decisions on behalf of whom? Christians will want to know how decisions are made and who is included in the process.

Human power today unfolds in a vivid tension between human creativity for potential benefit and human potential for creating peril. It exists in the tension between the pos-

From *Evangelical Lutheran Worship*: “... we confess that we are captive to sin and cannot free ourselves. We have sinned against you [God] in thought, word, and deed, by what we have done and by what we have left undone. We have not loved you without our whole heart; we have not loved our neighbors as ourselves.” (page 95)

sibilities of imagination and the dangers of misuse on a global scale. In response to such tensions, Christian faith recognizes that in Christ we, as his people, will sometimes be bewildered, even anguished decision makers. But it also teaches that we are at the same time redeemed decision makers. In the final analysis, this is the source of that Christian confidence which enables us to live with the ambiguities of our callings to responsibility. Decisions and callings may never be free of sin and limitation, but Christians need not fear that only righteous deeds will somehow make us right with God or save the world. This frees us to heed calls to responsibility and take up the tasks of critically engaging the unprecedented decisions and powers that genetic developments place before us.

## Invitation to conversation, prayer, and action



### QUESTIONS FOR DISCUSSION

- What do you understand by Christian vocation? Have you ever thought about the relation between your baptism and your Christian vocation? Name several of the callings you fulfill as part of your Christian vocation.
- In terms of genetics, what is the relation between the Christian vocation and various callings such as parent, scientist, farmer, financial officer?
- What do you think about the idea that Christians may sometimes be bewildered, even anguished, decision makers, keenly aware of limitations? What do you think about Christians as simultaneously redeemed decision makers? How is this helpful? How is it not?
- Action question: In which of your callings have you been most affected by the developments of genetics? What resources would help you fulfill your calling more effectively? How could your congregation help its members and communities to fulfill their callings better?

### Closing prayers

#### INVITATION TO INTERCESSORY PRAYER

Pray for those who seek to know what God's will is for their lives, and pray for those who strive to live out their calling in faithfulness.

#### PRAYING WITH THE TRADITION

Lord, make us instruments of your peace. Where there is hatred, let us sow love; where there is injury, pardon; where there is discord, union; where there is doubt, faith; where there is despair, hope; where there is darkness, light; where there is sadness, joy. Grant that we may not so much seek to be consoled as to console; to be understood as to understand; to be loved as to love. For it is in giving that we receive; it is in pardoning that we are pardoned; and it is in dying that we are born to eternal life. Amen.

(Prayer attributed to Francis of Assisi, who lived 1181-1226)

### Endnotes

1 President's Council on Bioethics. *Beyond Therapy: Biotechnology and the Pursuit of Happiness*. (Washington, D.C.: October 2003), p.2.

2 "Our Calling in Education" A social statement of the Evangelical Lutheran Church in America 2007, p.1.

# Human Power Today: Innovation and accountability before God

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

Into your hands, Almighty God, we place ourselves: our minds to know you, our hearts to love you, our wills to serve you. Into your hands, Incarnate Savior, we place ourselves: receive us and draw us after you that we may follow your steps; abide in us and enliven us by the power of your indwelling. Into your hands, O hovering Spirit, we place ourselves: take us and fashion us after your image. May your comfort strengthen, your grace renew, and your fire cleanse us in life and in death, in this world of shadows, and in your changeless world of light eternal, now and forever. Amen.

*(Evangelical Lutheran Worship, p. 86)*



### HEARING THE WORD

Philippians 2:1-11

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

This session explores the important question of what it means to be a human being in light of our relationship to God, and with an eye on how advances in genetics are interpreted in our society. The first section identifies some troubling ways of thinking about human beings related to what might be called “the gene myth.” The second then sketches Christian ways to think about being human in relation to God, the creation, and to one another in the contemporary world.



### Real life stories

1. Tina lost her hearing as a child. She attended schools for the deaf and learned American Sign Language, but is able to read lips and can speak fairly clearly. She grew up attending a Lutheran church where she was able to participate in worship only because of her ability to lip read. As an adult, she has found a congregation that includes a number of deaf members and has services that include sign language translation.

Since her college days at Gallaudet University, she has been active in the Deaf Culture movement, which views deafness not as a disability but as a kind of minority status similar to race, and also as a unique linguistic culture. Deaf Culture holds that there is nothing wrong with being deaf, only with how society has treated deaf people. While at Gallaudet, she was involved in protests over the appointment of a new university president who many students and professors believed was not sufficiently familiar with the culture of deafness, in part because she did not learn sign language until she was an adult.



Paul writes from prison to the Philippians. They are afraid he might die there. In these verses he proposes a way for them to live for Christ whether he is there or not.

What parallels do you hear between the ethical convictions Paul urges Christians to have (the mind of Christ Jesus) and the convictions that Christ Jesus had which brought him to the cross?

Theological anthropology is systematic thinking about what faith teaches about who human beings are and how we relate to God, others, and the rest of creation. In other words, it reflects on what Christians believe about human beings because of what they profess about God and God's work.

By *myth* here, we refer to a framework of assumptions or beliefs that surround science, but which have not themselves been scientifically demonstrated. The *gene myth* is a mindset that reduces everything significant about being human to the genes.

Tina is now hearing conflicting things from her friends and fellow activists about genetic testing and deafness. About 1 in 1,000 infants is born profoundly deaf and in about half of these cases, the deafness is due to a genetic cause. Mutations in many genes are involved, but the most common, accounting for about one in five deaf children, are those affecting connexin 26. Some in the Deaf Culture movement are concerned that the identification of genes that cause deafness coupled with new testing techniques will lead parents to choose not to have a baby because it would be born deaf. Others hope that the growing availability of preimplantation genetic diagnosis, (P.G.D.), a process in which embryos are created in a test tube and their DNA is analyzed before being transferred to a woman's uterus, will allow them to screen for genes that cause deafness, allowing them to choose a deaf child who will share in their culture.

Tina wonders whether it makes sense to allow these kinds of tests in either case. She wonders whether we should open the door to allowing people to select their children based on information about non-life threatening genetic traits just because technology may exist to do so. Should we open the door to allowing people to select their children based on information about non-life threatening genetic traits? She has discussed this with other members of her congregation and her activist group. Those in her congregation wonder what, if any, position their church has on this type of genetic testing and the potential for genetic selection of children.

2. *Cracking the Code of Life*\_Segment 15: Genetic Modification (use minute 1:38:40 to 1:44:14)

## How not to understand what it means to be a human being in this biotech century

The first two sessions of this study have explored what “is going on” in this biotech century, how we are all involved, and what is at stake. The next two sessions will explore ethical resources that Christians can draw on when evaluating choices regarding genetic research and development, which are likely to be the dominant mode of technological innovation in the foreseeable future.

Before we turn to ethical matters, however, we should explore some fundamental questions about ourselves as human beings. For Christians, the technical term for this kind of reflection is *theological anthropology*. Theological anthropology thinks about what it means to be human in light of what we know about who God is. Discussion about how we understand ourselves—our identity—may seem abstract, but in reality it dramatically and concretely affects daily decisions and judgments. Who we understand ourselves and others to be will directly affect what we do and how we relate to others. For example, if I perceive a homeless person as a child of God just like me, I am likely to respond to her in a way that is somewhat different than if I see her as “mentally ill,” or as “genetically determined.”

It's important from time to time to pay attention to questions of human identity. Only then can we decide which beliefs serve us well and which need revision. In particular, this first section explores some beliefs about genetics and human identity that are common in society, but that may be inaccurate or inappropriate.

### Gene myth

Much of the confusion about genes and human identity results from what may be called the *gene myth*. The myth is that our true humanity, or at least everything important about us, is “all in the genes.” The statement “My genes made me do it” hints at this, even when said tongue-in-cheek. The idea that we are *determined* by our genes is another example of the myth.

There are several variations of this myth (for more discussion of this, see session B2), but the main problem presented by the myth is the idea that whatever is *truly* human about humans can be reduced to the genes. Simplistic media coverage contributes to this reductionism, but so does scientific talk.

Scientists must reduce the subject matter they study into simpler pieces for purposes of investigation. For this reason, researchers necessarily look at the genetic code in isolation. This can lead, though, to belief that human beings can be fully described by what the gene code does. For example James Watson, co-discoverer of the double helix in 1953, and Nobel Prize winner, once told *Time Magazine*: “We used to think our fate was in our stars. Now we know, in large measure, our fate is in our genes.”<sup>1</sup> Genes do have a great deal to do with who we are, but it is all too easy to slip from that fact into the gene myth.

More significantly, such beliefs often lead to harmful outcomes. For example, some scientific studies have blamed poverty and criminality on genes. Others have explained low intelligence with genetic data. Claims such as these are dangerous because they allow racial and sexual categories and complex social problems to be reduced to genetic causes. In other words, categories or problems that are social in character are passed off as “natural” problems about which little can be done. Any talk that hints of “genetic determinism” or “essentialism” worries people of faith since it is not only false, but leads to human arrogance, harm to others, and reduces a human being to an “it.”

### Technological imperative and extreme individualism

Two other ideas have taken on new strength over the last two decades. The first is that of the *technological imperative* and the second is *extreme individualism*. Both are prominent beliefs or mindsets (working assumptions that frame thinking) in this society, and they must be named and appropriately challenged whenever they are used to champion genetic developments.

The technological imperative can be described simply. It is the belief or presumption that: “Because we can do something technologically, we should do it.” In other words, if new knowledge makes technology possible, then there is an imperative to make use of it. The general mindset of our culture supports the technological imperative. For example, this mindset can be seen in our eagerness to “let the market decide,” our emphasis on self-fulfillment, and our belief in the inherent goodness of change or unfettered enterprise.

Related to this technological mindset is a cultural emphasis on the rights of the individual. The concern for the individual and individual rights has brought many gifts to U.S. society, including an insistence on the dignity of the individual. It is problematic or even dangerous, however, when this concern for the individual becomes extreme. Extreme individualism can be defined as a mindset in which the individual self is seen as the all-important measure of life. Extreme individualism looks to the self for the meaning of life and for moral guidance. It makes absolute the values of self realization or self-fulfillment. It is exemplified in this society by the growing insistence on private choice, and can lead to the presumption that moral decisions should be made in terms of personal self-fulfillment alone. This mindset can be seen in the common phrase, “do your own thing.” Such extreme individualism contradicts biblical notions which stress the good of the human community as primary and fundamental.

There are many examples of the dangers that arise from linking the technological imperative with extreme individualism. One example can be seen in the area of reproductive choice. Reproductive choice is a good thing, but not when it is seen as an absolute. It can, in fact, become dangerous if the technological imperative is linked with extreme individualism. In that case, the fact that a new reproductive technology can be successfully marketed becomes sufficient justification for doing so, and for concluding that it is ethically acceptable. It is complicated. On the one hand, it seems right to give parents *all* options as they become possible and available. On the other hand, the desire for the “latest” and “best” for *my* child could lead to the practice of “designer babies,” and this practice could be a new form of *eugenics*.

The technological imperative: The mindset, belief, or presumption that because we can do something technologically, we should do it.

*Eugenics* literally means “good genes,” and the term can indicate simply the study of hereditary improvement. It usually refers, however, to any strategy for directing human evolution through the transmission of “desirable” traits while impeding the transmission of “undesirable” ones. The most well-known examples are the eugenic practices fostered by German Nazism. It must be pointed out, though, that many nations, including the U.S., have had eugenic programs. Eugenic strategies include selective mating, prenatal testing, selective abortion, forced sterilization, ethnic cleansing, and others.



## Theological reflections on what it means to be a human being

### Christian Contrasts

Christian views about what it means to be human before God look dramatically different in crucial ways from the views just discussed. In contrast to genetic reductionism, for instance, Christian anthropology understands human nature as fundamentally dynamic and relational. In contrast to extreme individualism, we learn from Christ that to be human is to participate in meaningful relationships. The biblical understandings of God, as summarized in the Trinity of Father, Son and Holy Spirit teach us that God is relational. The first person of the Trinity is the Father of the Son, who in turn is the Son of the Father, while the Spirit is the one who proceeds from the Father and the Son (Nicene Creed). Only God is able to pull off this awesome relational mystery; to believe in a Trinitarian God is to believe in a relational God. No wonder relationships are inherent in nature in general (life thrives in relationships, in ecologies) and among human beings in particular! Being human is a collective and communal activity.

Again, rather than the focus on what genes determine, Christians focus on God's creative presence dynamically at work throughout the ongoing process of creation. Humans are created to participate in this creative process, a participation made possible in part through genes themselves! The human place in creation has too often been misunderstood as one of dominating and exploiting. But the point of Genesis 1:14-28 or Psalm 1:1-9 is to show the way that God relates to the creation and the blessings and vocations God gives to creation. All living creatures are given the vocation of being fruitful and multiplying. Three types of creation are given the task of regulating other types of creation. The sun regulates (rules) the day, establishing times and seasons, the moon regulates (rules) the night and human beings regulate (rule) birds, fish, and every living thing on the earth.

This regulation by men and women is to further the vocation of the rest of creation. By providing order, rather than chaos for the creatures, men and women support and maintain the fruitfulness of all of God's creatures. In the original language of the Old Testament, this ordering is not akin to domination as "lording it over everything." Rather it is a stewardship (a working under someone else's authority) according to the blessing and goodness God has already established in creation. In order to further the creation God gives human beings such gifts as knowledge and imagination so that we can be nurturing stewards. God's gifts enable human beings, in subtle yet fundamental ways, to even introduce novelty into God's ongoing creative enterprise for the purpose of serving in God's ongoing enterprise.

In stark contrast to those who think human beings can use these gifts to progress to a state of near perfection (even near-immortality!), however, Christian doctrine teaches a more realistic attitude. Lutheran Christians in particular adamantly profess that mortality and imperfection are integral to what it means to be human. A key idea in the Lutheran Reformation is that humans are always simultaneously "saint and sinner"—beloved and claimed by God at the same time that they are full of faults and limitations. Human efforts, while vitally important and needed for the good of society and creation, cannot ultimately change (save us from) this fundamental reality. Such a theological view provides a needed measure of humility to our bold aspirations. No genetic discovery or treatment will alter the fact that human beings are both precious and also mortal creatures. Can we respond to suffering and be creative while we are here? Absolutely! But as people of faith, we do not see (or seek!) immortality or absolute perfection in this life.

### Jesus Christ as the true image of God for humanity

Central to the Christian understanding about what it means to be a human being is the non-negotiable conviction that all human beings are created in the image of God. Christian belief in the inalienable dignity of each human being is derived from that conviction. At the same time, however, Christian belief affirms that humans are bound by sin. Christians

recognize that human beings live in the tension between bearing the image of God and yet missing the mark (the target) of what God intends for us.

Jesus Christ is God's solution to that dilemma. By raising Christ, God frees us from the bondage to sin and makes possible our acting according to the image of God revealed in Christ. Christ Jesus, who did not consider equality with God something to be exploited, who was obedient even to death on the Cross and who was raised becomes our example since we now share the mind of Christ (Philippians. 2:1-11). In a perhaps surprising way, it may be said that in Christ God reveals to us who we actually are! By faith we participate in that image in an anticipatory way, and so Christians understand the image of God as both gift and calling, as grace and vocation.

The image of God has been equated with the human capacity to reason, and reasoning is important. But contemporary Lutherans tend to take their clues about this from scripture and the early Reformers, like Martin Luther, for whom God's image in humans was the potentiality to enter into relationship with God and to serve others and the earth. This becomes clear in the Reformation emphasis on God's love as the source of love that humans extend to the neighbor. It is also clear in Luther's admonishment to be "Christ's" to each other, which simply expresses the central purpose in life as loving the neighbor because, and as, Christ has loved us. The idea is not that every believer should become a clone of Jesus, but that we become the *kind* of human beings that Jesus Christ was, which is possible since his spirit dwells in us (e.g., 2 Corinthians 3:17-18, 1 Corinthians 6:19, Galatians 5:25).

The Christian understanding that God was incarnate in Jesus also teaches us that God became a particular human being, at a particular time in history, within a given culture. This same "particularity" is true of all human beings since each of us is shaped by historical, social, and economic contexts. We are not *determined* by these, but cultural values significantly shape not only individuals but also the institutions and manifestations of a people's spirit. This is important to remember when we talk about science and technology. They are shaped by the spirit of the culture that undertakes them. The type of biotechnology that we produce as a society, or even the types of research funded, will be dramatically influenced by the spirit behind them.

### More than individual sin

A widely respected secular thinker, Francis Fukuyama, names a key fear of many regarding genetic developments when he says that:

[T]he deepest fear that people express about technology is...a fear that, in the end, biotechnology will cause us in some way to lose our humanity—that is, some essential quality that has always underpinned our sense of who we are and where we are going, despite all of the evident changes that have taken place in the human condition through the course of history. Worse yet, we might make this change without recognizing that we had lost something of great value. We might thus emerge on the other side of a great divide between human and post-human history and not even see that the watershed had been breached because we lost sight of what that essence was.<sup>2</sup>

Christians do not fear that the image of God will be lost in some kind of post-human history, but they do worry about the lure of society's idols. This lure has always been powerful, but it becomes even more so with increasing human power over the genome. They fear that, rather than embodying the good that God intends human power to serve, this expansion of human activity might end up putting our very bodies at the service of our economic and social idols.

Christians often think about sin at an individual level, but Christian teaching also points to the magnified power of sin in corporate endeavors. The lack of personal accountability within large scale activity can magnify sin's power and consequences. We must remember that genetic science and technology can be social instruments of God's creative and healing presence in the world, but they can also be an occasion for great harm. They can be pursued for the selfish interests of the few at the expense of the many.



Christians begin and end with the cross and Resurrection of Jesus Christ. We should not look to human aspirations or to nature for marks of the divine to guide our ethics. Those places reflect back to us the idols we carry within. Through Christ we can perceive divine creativity and redemption at work in nature, and understand what it means to live out our vocation. In this sense, Christ is to be our guide in the age of genetics, as in every age. Guided by his example and in this confidence, Christians find a ground for choice and action in the age of genetics that balances risk and boldness with humility and caution.

## Invitation to conversation, prayer, and action



### QUESTIONS FOR DISCUSSION

- Choose one of the ways that genetics and human nature can be misunderstood as explored in section one above and discuss it. The following are some possible discussion starters:
  - What should the church's public stance be in relation to beliefs like the technological imperative or extreme individualism? How can it speak without appearing to be against enterprise and development?
  - In what ways is it helpful to identify these dangers as this society makes decisions regarding genetic developments?
- Choose one of the ways Christians talk about human beings as described in section two and discuss it. Here are some possible questions:
  - Do these discussions of the image of God and the place of sin seem consistent with scripture and with other Christian thinking?
  - In what ways are they helpful to you for thinking about decisions that must be made about the use of genetics in this society?
  - Are there aspects of these beliefs that should be very challenging to U.S. culture? What are some of those?
- Action question: How could you find out more about products being created using genetic technology? How could you and your congregation become more aware of legislation pending in your state or at the federal level that relate directly to genetics research and the use of genetic products, whether medical or agricultural? How could you study them? What action could be taken if this legislation seems faulty?

## Closing prayers

### INVITATION TO INTERCESSORY PRAYER

Pray for those who labor in making laws, enforcing laws, and in carrying out justice.

### PRAYING WITH THE TRADITION

In you, Father almighty, we have our preservation and our bliss. In you, Christ, we have our restoring and our saving. You are our mother, brother, and savior. In you, our Lord, the Holy Spirit, is marvelous and plenteous grace. You are our clothing, for with love you wrap us and embrace us. You are our maker, our lover, our keeper. Teach us to believe that by your grace all shall be well, and all shall be well, and all manner of things shall be well. Amen.

(Prayer of Julian of Norwich, who lived about 1342 to 1413)

## Endnotes

- 1 Jaroff, Leon. "The Gene Hunt." *Time Magazine* (March 1989), 67.
- 2 Francis Fukuyama, *Our Posthuman Future: Consequences of the Biotechnology Revolution* (New York: Farrar, Straus and Giroux, 2002), 101.

# Christian Responsibility Today: Sources for guidance

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

Direct us, Lord God, in all our doings with your most gracious favor, and extend to us your continual help; that in all our works begun, continued, and ended in you, we may glorify your holy name, and finally by your mercy bring us to everlasting life; through Jesus Christ, our Savior and Lord. Amen.

(*Lutheran Book of Worship*, p.49)



### HEARING THE WORD

Luke 10:25-37

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

This session considers the moral or ethical<sup>1</sup> resources that Christians can turn to as they ponder the developments and social issues with which genetics confronts society. The first segment explores Lutheran convictions about scripture as a resource for the moral life, while the second identifies values that all people of good will claim as touchstones for living in the genetics age. The last segment concludes by looking at several relevant moral resources taken from established social teachings of the ELCA.



### Real life stories<sup>2</sup>

1. Phil Ramsey has just been hired as the chief financial officer for Genetic Development Corporation, a biotechnology company located in the Boston area. He has spent most of his career working with fast growing businesses. He has been involved in public financings, initial public offerings, and several venture capital firms, but this is the first time he has been extensively involved in the biotech industry. He is a member of a Lutheran congregation and is pondering what his faith means for his new work.

He knows that genetic testing creates new challenges with which society must deal. He also knows that some people portray him and his co-workers as “mad scientists” or “greedy entrepreneurs” bent upon the advancement of medical technology regardless of its impact on society. But he knows that the individuals who make up the biotech workforce very much reflect society as a whole and are not uniform in their views and beliefs.

His experience indicates, in fact, that the biotech industry includes a significant percentage of people of faith. Moreover, he is coming to believe that those who have chosen this industry did so because they want to accomplish something purposeful with their careers; they want to know their work changed peoples’ lives for the better. He also knows that America does not exist in a vacuum, and that, whatever the concerns with the development of therapeutics based on genetic markers, it will be done somewhere by someone.



Both Jesus and the lawyer who questions him concur on the heart of the Law: loving God and neighbor. These principles are found in Deuteronomy 6:4-7, Leviticus 18:1-5;19:13-18. New Testament parallels for this passage are Mathew 22:34-40; Mark 12:28-34.

How does Jesus change the lawyer’s need to identify a specific neighbor into a value of being a neighbor to anyone in need?

Ethicists (individuals whose work is dedicated to thinking and writing about what is good, right, and fitting) generally make a useful distinction between morals and ethics (see endnote 1), but you may think of them interchangeably for the purposes of this study.

Social context refers to broad features that shape any human activity like culture or the language used. Social location refers to the idea that human beings are “located” in many social relationships and identities that shape their self-understanding, values and aspirations, and their perceptions of others and the world. Examples of these relationships include race/ethnicity; socio-economic class; gender; religious affiliation; mental/physical abilities; and age.

As he ponders these facts, his work, and what he hears at church, he has settled on two questions he wants to ask his pastor and fellow congregational members:

How can our Lutheran church best position itself to (1) provide input to the industry and the individuals in it from a Christian point of view, and (2) impact decisions in a positive fashion?

What does the Christian point of view say morally about the work he is now doing, and how can that be communicated in a language people in the industry can understand?

2. *Cracking the Code of Life* Segment 13: DNA Databases (use minute 1:25:29 to 1:31)

## Christian resources for ethical deliberation

We have called upon Christian resources from the very first session of this study. But as Christians respond in gratitude to the experience of God’s grace and seek to live out their callings and responsibilities, we look for specific moral guidance. Fundamental guidance of this kind is found in scripture and in our Lutheran Confessions as faithful interpretations of scripture.

### Scripture as authoritative source and norm

For Lutheran Christians, the Word of God is a living Word active before the foundation of this earth, still active in this very moment and in futures and in worlds unimaginable to us. That which was revealed to us in the Bible is the written word of God. It is a witness to what God has done in the past for many people. By the values it expresses we learn how God has acted in the world. By the repeating pattern of God’s mercy and judgment we learn how God would have us live—with rejoicing and humility before God and with fellowship and investment in our neighbors’ trials and joys.

We have also a much stronger connection with God in our living Lord Jesus Christ, seated at the right hand of God, for he does more than teach. He forgives, renews, invigorates and calls us to our vocations. No written word can summarize all he has done for us as the living word of God. We experience his love and his spirit daily.

As a result of our devotion to Christ, our Lord, we hold dear those texts of the Old and New Testaments which witness to the proclamation of God made flesh in our Lord and Savior Jesus Christ. It is for this reason that we acknowledge the Bible as the authoritative, inspired source and norm of both life and the Christian proclamation. It is for this reason that the Bible is the fundamental source for Christian moral guidance, even though Lutherans do not consider the Bible first or foremost a rule book, but as the witness to the power of God in all God’s dimensions.

Lutheran Christians also recognize that these texts witness within the limitations of their authors’ human creativity and sinfulness, culture, social status, age, race, nation, language, and particular intended audience. As a result, Lutherans do not consider the Bible as the only means by which God speaks to us. Its witness is source and norm, but not the sum total of moral guidance.

This recognition of social context and social location behind the biblical authors’ witness is a great blessing in our study of genetics. It teaches us to be listening for God’s guidance in many other places. It also reminds us of our own limitations in any statements that we might make. (For instance, even while writing this study, the task force acknowledges that its witness to the blessings and limitations of the genetic challenge will not be that of all peoples or all nations or all times.)

Additionally, recognition of the role of social context and social location means we can take seriously what the Bible has to say about matters related to genetics. While we will not see the words “genetics” or “genome” in Christian scriptures, we can examine biblical texts that speak to ancient concerns that still resonate in the twenty-first century, e.g., (in)fertility, hybridization, crop failure, illness and healing, confronting mortality and death. As we learn both about genetics and the scriptures, we will be able to identify how God engages such concerns with creativity, justice, and mercy.

## Guidance from scripture

As the fundamental source for moral guidance, what is scripture's basic principle for the moral life? Christians have generally looked to the *double love commandment* for this: "You shall love the Lord your God with all your heart, and with all your soul, and with all your mind...and a second is like it: 'You shall love your neighbor as yourself'" (Luke 10:27 and Matthew 22:37, 39). In other words, both the Old Testament and Jesus teaches that *all* individual and corporate actions should unfold from loving the God who has first loved us, and should be directed at care for neighbors who need to be loved. Or to tie it to the idea of vocation, the double love command grounds both faith in God and the baptismal vocation to serve others. Insofar as we have faith, we cannot help but be active in serving. Insofar as we have faith, we know that bringing good to the world is what God is doing and we know that we are called to do the same.

Sometimes this statement about love of neighbor can be understood as if the Bible is concerned primarily about individual lives. But Scripture is quite clear that God's priority is to address believers in their corporate and social life. We find a strong example in the words of the Lord God given to the prophet Amos (Amos 5:1-24) "...but let justice roll down like waters and righteousness like an ever living stream." God governs the whole world and commands that justice be done in the social dimension of life. God is just as active in the social arena as in governing the Christian heart.

Scripture also provides a vision of the future that directs Christian love and justice seeking in the present. This vision is grounded in the belief that God raised Jesus from the dead as the first born of all creation, and it is vividly described in some places: "[God] will wipe every tear from their eyes. Death will be no more; mourning and crying and pain will be no more, for the first things have passed away" (Revelation 21:1-4. See also Isaiah 25:6-9; 65:17; 66:22.). Scripture's guidance, then, includes this vision of human health and wellbeing as the end goal for all creation. We do not create this future, but in gratitude for its promise, Christians are to invest creative energies in approximating this vision of salvation and in creating fragmentary yet real illustrations of it now. Living in hope, Christians pursue an ethic that seeks to anticipate in the present those values integral to God's promised future of wellbeing.

Even while guided by that vision of God's future, the crucifixion of our Lord Jesus teaches us that we live in a world of sin and so must adjust to the realities of life as it is now. Neither the good news of God in Jesus Christ nor a positive end-time vision from Scripture are enough without our continuing the first vocation God gave us, to order the world for the good of all species and the earth itself. To aid us in this task, the Bible also presents guidance through the 10 commandments and other examples of the law. (Exodus 20:2ff) God works through the gospel where appropriate, but also works through the demands of law. Lutherans thus talk about God's work through both law and gospel. Mindful of both, the Christian ethic can be summarized as "faith active in love seeking justice."

## The need for principles

Yet, is loving the neighbor or knowing the 10 commandments enough to help us decide exactly how to respond to social dilemmas and particular challenges? We need other principles and guidance that can assist us in translating biblical teaching into proper actions and nitty-gritty decisions. Christians, like other people, need relevant knowledge and a whole array of moral principles and standards for making daily-sized decisions about:

- what genetic research to support with tax dollars,
- which scientific or business efforts to encourage,
- whether to use transgenic products,
- if/when to seek out genetic testing.

Commonly shared ethical principles from social life can aid us in thinking about those kinds of decisions, as long as they express dimensions of love and elements of God's commands.

## Commonly shared resources for ethical deliberation

When Lutheran Christians seek guidance for engaging complex questions related to genetics, it is helpful to remember that we have a positive view of humanity and creation as good and beloved by God. Because God has bridged the distance to come to humankind, we know that we can draw upon human reason (a God-given gift common to all human beings regardless of any faith tradition) to address crucial ethical issues. As long as this affirmation of human reason and intellectual capacities does not encourage us to put our ultimate trust in our own abilities or to misplace faith in God, Lutherans will not reject such commonly shared human wisdom.

If human reason is a source for moral guidance, then we are free to honor and adopt some of the principles we need. Moreover, the Christian use of commonly shared principles allows us to communicate with others in the public arena, whether Christian or not. We lift up here two significant values or principles important for discussing genetics and public policy.

### The common good

The first value is the *common good*. Political thought has long centered on this idea as the prime goal for public policy and an important criteria for evaluating public policy. It is crucial to be able to ask: Does this or that policy contribute to the good of all? If not, who benefits and why? Christians are very comfortable with this idea since it is implied in the commands to love and do justice. As the Apostle Paul writes, “So then, whenever we have an opportunity let us work for the good of all” (Galatians 6:10). The common good is not a magic criteria, but it does serve as a touchstone that can guide and help us evaluate. It is quite legitimate to look at a possible use of genetics and affirm it because its use will benefit the common good. The opposite is also true, and in that respect this value can rule against some genetic developments because they do not significantly serve the common good.

### Human dignity

The second value, *human dignity*, has already been mentioned above. Dignity may be defined, in brief, as the quality or state of being worthy of esteem or respect, and thus due appropriate obligations and duties. Christians ground their affirmation of human dignity in the evidence of God’s love that creates us in God’s image. Belief in human dignity is widespread in this society. It is one of the common assumptions this society shares, especially from the standpoint of law. The societal assumption that dignity is innate permits national codes of law to uphold the right of every individual regardless of their wealth, status, or mental condition, even if this is imperfectly done.

But there is another widely-shared meaning beyond the idea of an individual’s inborn legal dignity. Human dignity, it should be noted, is more the result of a relationship than simply an invisible legal mark on an individual. A newborn needs others if it is going to survive and thrive. Parent, family, friends, and others provide attention and affection, and over time these contributions to the child’s life help create a sense of dignity. Human dignity, then, is not just an innate individual thing but arises from the activity of a community. This is important not to overlook!

Nor should it be forgotten that dignity also has a future orientation. The Christian tradition is especially aware of this aspect because of the idea of the resurrection of the dead. Still, even non-Christians evidence such a future orientation whenever they express some sense of responsibility for “our children’s children.” Human dignity, in this sense, comes from the future or end-goal. Christians are assured of this in God’s saving activity; dignity is due other humans because of what God will finally make of us.

The principles of the common good and human dignity should be kept front and center in any discussion or decision about the use of genetics. Christians may enrich these secular concepts with specifically religious meanings, but we use them as commonly shared values in the public arena.



## Established resources

One of the primary ways that the ELCA brings together scriptural guidance and commonly shared concepts, like the common good, is through its social teaching and policy documents. The most basic of these documents are called social statements. These statements provide frameworks and principles for considering social issues. They are not new creeds or confessions, and are always subject to testing as to whether they are faithful to Scripture and our heritage. Yet, their role is to guide the formation of Christian conscience, to guide policy-setting for this church, and to guide Christian advocacy and work as a public church. As you probably understand by now, this study is one of the steps in moving toward such a statement on genetics. Even while charting new territory, this statement can draw on previous statements for some general direction and established principles. The following three points illustrate such themes that we can rely on.

### Church as community of moral deliberation

The character of this study is guided by the conviction that this church is a *community of moral deliberation*. Simply put, solid ethical reflection is not a solo sport. We do not do it well if we only always sit alone with our ideas, concerns, and the scriptures as we contemplate moral questions. We all have partial vision, and listening to, learning from, and sharing with others helps us expand our perspectives on and understanding of very complicated ethical problems.

The concept of a community of moral deliberation was developed outside of religious institutions, but it is now part of the ELCA's self-identity as a Christian community.<sup>4</sup> This is also an important commitment in the age of genetics since the moral and social issues are so complex. Part of taking responsibility today is being open to engage in such ethical deliberation in order to inform the best possible decisions. The church is one of the best places to have such conversations because we can leave partisanship at the doors of the church and discuss as people united by Christ, even when not united by our perspectives. This then raises the question as to whether such a commitment to honest give and take should stay inside the church doors! The question becomes: on the matter of genetics (and other issues too!) should we also extend this commitment to moral deliberation across vocations, religious traditions, political affiliations, geographic borders, and socio-economic contexts?

### Valuing lives

On the controversial matter for genetics of “when human personhood begins,” the ELCA has no stated position. The ELCA statement on abortion does observe that: “The strong Christian presumption is to preserve and protect life,” and indicates further that “human life in all phases of its development is God-given and, therefore, has intrinsic value, worth, and dignity.” It also states that although “abortion raises significant moral issues at any stage of fetal development, the closer the life in the womb comes to full term the more serious such issues become.”<sup>5</sup> These statements seem to suggest a concern for both the protection of life and the developmental nature of human personhood. Given that both kinds of language are in the statement, it is fair to ask: should this church oppose research that creates embryos solely for the purpose of extracting stem cells and should it oppose all non-therapeutic embryo research? Should it be open to genetic research on early stage embryos that have already been created and will never be used?

Beyond these contested questions around the beginning of life, the presumption to preserve life clearly includes valuing all human lives. The lives in question include those in the U.S. and abroad who suffer poverty, lack healthcare, live amid regional warfare, and so forth. This is important in terms of genetic policy questions because of the huge level of resources and the sometimes limited accessibility to the results. This is especially relevant when we remember that human genetic research and treatments are largely carried out among the affluent in the U.S. and Western Europe. Millions die each year in impoverished countries from diseases (malaria, TB, HIV-AIDs) and conditions (poverty, hunger, malnutrition) that do not need a genetic solution or discovery to be effectively addressed.

In the ELCA, there are three types of social teaching and policy documents. The most authoritative are framework documents called *social statements*, while the shorter and more topical teaching documents are called *social messages*. The third kind, called *social policy resolutions*, are brief and very focused. “These documents arise from and address the changing circumstances of the world in light of God’s living word of Law and Gospel. With the aid of contemporary experience and knowledge, they bring this church’s understanding of its faith to bear on social issues.”<sup>3</sup>

“As a community of moral deliberation, the Church seeks to “discern what is the will of God—what is good and acceptable and perfect” (Romans 12:2). Christians struggle together on social questions in order to know better how to live faithfully and responsibly in their callings. Processes of deliberation need to inform and guide this church’s corporate witness in society.” (*Church in Society: A Lutheran perspective*, p. 7)

So one question is: should the presumption for life in tandem with the principle of justice mean that this church should insist that questions of social priorities and systemic injustice be used to evaluate whether or not to proceed with particular applications of genetic medicine and biotechnology? For example, should this church insist that the delivery of a new procedure, like a genetic test for newborns, answer the question: will this procedure be delivered in a way that makes it accessible to all expectant parents around the world?

#### Four principles of justice

The existing social statements of the ELCA have already crafted some of the principles we should call on as the ELCA speaks to a society in the biotech century. Four principles of justice—participation, solidarity, sufficiency, and sustainability—are clearly visible in the social statements on the environment, peace, and economic life and each has significant overlap with concerns encountered in the area of genetics.<sup>6</sup> All four express values evident in the speech and actions of our Lord Jesus toward those around him and even in his regard for the creation. These four mediating principles of justice constitute a pattern of discernment in the ELCA for a social ethic. This social ethic, while not fleshed out in detail, still makes it possible to address social issues in a coordinated and comprehensive way. It provides a basis for assessing conflicting moral questions and choosing between the varied goods of life (physical, social, personal goods, and so forth). In this sense, these four principles could be said to articulate a core ethics of “faith active in love through justice” for ELCA social policy.

- *Solidarity* affirms a sense of kinship with the whole web of God’s creative activity, and it should cultivate actions that seek harmony among individuals, cultures, and all living things on the earth. It includes *standing with* the victims of natural disaster, and presumably would include *standing against* other assaults on human wellbeing such as disease and disability. It would seem to imply both moral integrity and the courage to stand with and for creation.
- *Sufficiency* means meeting the basic needs of humans and other life because life comes *from God for* all. In a world of finite resources, sufficiency means that those with more than enough should share with the needy. In a globalized world of modern powers, this would seem to suggest that we must find ways so that all have enough.
- *Sustainability* means providing an acceptable quality of life for present generations without compromising that of future generations. In the past, Christians have supported this principle by appeal to the Sabbath and jubilee laws (Leviticus 25:8ff.). Today it includes a scope of accountability that ancients could not have imagined due to issues of population, power, and knowledge. These changes in the human condition call for revisions to what sustainability means in ways we are only beginning to consider.
- *Participation* recognizes that humans are part of a vast, interdependent, and created community of life. This principle calls upon the church to be a community of moral deliberation where the needs of all living things are heard—actual, imagined, present, and future. The interests of the entire community of life must be considered.

Each principle makes its own distinct claims which both support and stand in constructive tension with the others. Together these principles reinforce the sense of holism and interdependence needed in an age of genetics. For instance, sufficiency guides the present while sustainability looks to the future, and together they give due to factors of both time and consequence. Solidarity entails care and accountability for the interdependence of life. In this way all living things are therefore accorded moral standing and rights. It seems right then to ask: in light of these principles should this church stand for setting limits and establishing obligations over the powers that genetic knowledge grants humans?



## Invitation to conversation, prayer, and action



### QUESTIONS FOR DISCUSSION

- What have you learned about the use of scripture in moral deliberation from the discussion above? Have you ever thought about the double love command or the passage about justice as the starting place for the moral life? What did you find helpful in this exploration? What was missing?
- Choose either the common good or human dignity from section two to discuss. Where does this idea show up in public discussions of social issues or policy? Where are they missing? Do you believe these values are relevant and beneficial for evaluating the use of genetic technology for business, commerce, and public policy?
- Choose one of the four justice principles just highlighted and discuss it. Here are some possible questions:
  - Does this principle seem consistent with scripture and with other Christian moral values?
  - Can you see how it could help guide reflection in a social statement on genetics?
  - How could it help answer the questions posed by “Phil Ramsey” in “Real life stories” above?
- Action question: Has your congregation ever had a Bible study dedicated to the ways scripture should be used in making moral decisions? How did you do this study? If your congregation has not, what issues of scripture and moral values, especially related to genetics, might appeal to your congregation?

### Closing

#### INVITATION TO INTERCESSORY PRAYER

Pray for those who work in the field of biotechnology as educators and researchers; in production and marketing as CEOs, CFOs, and Boards of Directors.

#### PRAYING WITH THE TRADITION

Power of the Eternal Father, help me. Wisdom of the Son, enlighten the eye of my understanding. Tender mercy of the Holy Spirit, unite my heart to yourself. Eternal God, restore health to the sick and life to the dead. Give us a voice, your own voice, to cry out to you for mercy for the world. You, light, give us light. You, wisdom, give us wisdom. You, supreme strength, strengthen us. Amen

(Prayer of Catherine of Siena, who lived from about 1347 to 1380)

### Endnotes

1 Morals are the personal and social customs, practices, and beliefs about what people should do and be. Ethics can be defined, then, as sustained critical reflection upon morals; it suggests systematic-like thinking about what is good, right, and fitting.

2 These individuals and scenarios are fictitious composites based on real circumstances and conversations.

3 *Policies and Procedures of the Evangelical Lutheran Church in America for Addressing Social Concerns*, 1997, revised 2006, p.10

4 *The Church in Society: A Lutheran Perspective*, p. 6. A social statement of the Evangelical Lutheran Church in America, 1991.

5 *A Social Statement on Abortion*, pp.2-4. A social statement of the Evangelical Lutheran Church in America, 1991.

6 There are nine social statements of the ELCA. The key ones relevant to this point include: *Caring for Creation: Vision, Hope, and Justice*, 1993; *For Peace in God's World*, 1995; and *Sufficient, Sustainable Livelihood for All*, 1999. More information is available at [www.elca.org/socialstatements](http://www.elca.org/socialstatements)



# Toward a Lutheran Ethic in the Age of Genetics

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

God Almighty, Father of our Lord Jesus Christ, grant us, we pray, that we may be grounded and settled in your truth by the coming of the Holy Spirit into our hearts. That which we know not, reveal; that which is wanting in us, fill up; that which we know, confirm; and in all things keep us blameless in your service, through Jesus Christ our Lord. Amen.

(*Evangelical Lutheran Worship*, page 86)



### HEARING THE WORD

Romans 12:1-8

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

This session brings together insights from previous sessions and invites reflection on the nature of Lutheran ethics in the age of genetics. It first presents elements for a moral framework, and then invites you to exercise your moral imagination and judgment in evaluating these principles by trying them out. It concludes with a reminder of the bedrock of faith, life, and action—the gracious and justifying call of God.



### Real life stories

(choose one for careful reading and discussion use)

1: Prenatal genetic testing

Pamela is 25, married, in good health and 18 weeks pregnant. A few days ago she learned that a much younger half brother (age 2) has been diagnosed with a disease she and her family had never heard of: Hurler-Scheie Syndrome. Understandably, her father and step mother are devastated. But there is more.

They shared with Pamela some of the things their pediatrician told them about this disease: Hurler-Scheie is characterized by multiple organ and tissue deterioration, limited mobility, gross facial features, hearing loss, and mental retardation. Death usually comes by age 10. There are no known cures for it. What is most worrisome to Pamela, though, is the knowledge that she could be carrying this gene.

Pamela contacts her obstetrician immediately who tells her Hurler-Scheie Syndrome is an autosomal recessive disorder (see the Primer near the back of this study, p. 134). Pamela finds this encouraging because it means both parents must carry the trait for an offspring to be affected. Although Pamela has a 50 percent chance of being a carrier, it seems unlike-



The word, “sacrifice” in the reading means “offering.” In Jewish and Gentile culture, these altar offerings were often the slaughtered bodies of animals. Paul appeals to the believers to be living offerings instead, taking upon themselves the pattern of Christ’s daily obedient faithful witness to God.

How might “being renewed in our minds” to share the mind of Christ stand opposed to thinking highly of yourself? (12:3)

ly that her husband Chet is also a carrier. The odds are only about 1 in 60 that he is, and even then, the risk of an affected child is only 25 percent. Still, a relatively blissful, much anticipated pregnancy has been filled with fear and anguish. What should she do?

Her physician tells her that the usual process would be to test both her and her husband to see if they are both carriers. But, since she is already well into her pregnancy, an immediate test could be done on the fetus which could determine the presence of Hurler-Scheie Syndrome. If the fetus tests positive, it would thereby confirm that both parents are carriers. After painstaking discussions, in which they consider the pros and cons of knowing vs. not knowing their fetus' genetic status, Pamela and Chet agree to a fetal test. Reluctant to part "the veil of innocence" and risk even more devastating news, they agree that knowing would be much preferred to waiting out the pregnancy in suspense.

After two anxious weeks awaiting lab reports, their worst fears are confirmed. Defying the above odds, their child is diagnosed with Hurler-Scheie Syndrome. Since Chet, too, has now been confirmed a carrier, it means there is a 25 percent risk that any future offspring of this couple will be afflicted as well. This news suddenly thrusts them into yet another dilemma: will they carry through with the pregnancy or elect to abort it? Pamela and Chet are crushed.

In two and one half weeks their world has been totally upended. They feel alienated from family and friends, even from the child they are anticipating. Now it seems like a lose/lose situation: either they end the pregnancy or have a child who will "be born dying." Moreover, they will need to give serious thought to future pregnancies. At this moment in their lives, church is about the farthest thing from their minds.

As fringe members of Nazareth Lutheran Church, they barely know their pastor. However, news such as this travels fast in a small community. Their pastor hears of it and decides to take the initiative and contact them. Though surprised to see her, the couple is pleased by their pastor's interest. Except for recent contacts with their doctors and a genetics counselor, they have kept pretty much to themselves lately. This unexpected pastoral visit offers them a welcomed opportunity to process things more slowly in the familiarity of their own home. After a brief but helpful visit in which the pastor listens, Pamela and Chet agree to meet with her again in three days to talk through together at some length what they should do.

## 2: Labeling for genetically modified food sources?<sup>1</sup>

In early 2008 The Food and Drug Administration announced: "Extensive evaluation of the available data has not identified any subtle hazards that might indicate food-consumption risks in healthy clones of cattle, swine, or goats." The FDA concluded that consuming milk and meat from cloned animals does not pose a threat to human health, narrowly finding that there may be limited risks from milk and meat from newborn cattle clones. It also put off making a decision about milk and meat from cloned sheep pending further study and information.

This decision opened the door to the possibility that, within a few years, milk and meat from cloned animals could be on grocery store shelves. The FDA also explicitly stated that since these products were deemed safe (with the limited exceptions mentioned above) they would not need to be labeled.

Although cloned milk and meat products will not reach grocery stores for some years, Representative I.M. is confronted with a choice now. Several of his colleagues have invited him to consider co-sponsoring a food labeling bill that would require all genetically modified and cloned products to be labeled. This would include not only cloned milk and meat, but also products that include genetically modified grains.

Congressman I.M. represents a farming and ranching district in the Midwest. Farmers in his district grow genetically modified corn and soybeans, and have encountered difficulty in selling their grain on world markets because of restrictions on genetically modified grain imports in the European Union and other parts of the world. Many of these farmers believe strongly that their products are safe and healthy, and that genetic modifi-

cations have led to significant increases in yield that are necessary if the U.S. is to continue as a leading grain producer. However, organic farmers in I.M.'s district have complained that genetically modified grains pose a threat to their organic status due to the drift of pollen from modified plants in neighboring fields.

In addition, cattle owners in I.M.'s district are gearing up to clone bulls that they believe would lead to herds of cattle with significantly increased meat production. Others are less certain of the benefits of this technology and support the position of the National Farmers Union that "consumers have the right to know if the food they feed their families comes from a cloned animal."

Representative I.M. is concerned that the scientific evidence about both genetically modified crops and cloned animals does not point to a clear conclusion that they pose a threat to human or environmental health. Labeling, pending further study of these impacts, seems to provide a middle way, allowing consumers to make informed decisions, and allowing for easy identification if products are later deemed harmful and need to be pulled from the market. However, many of I.M.'s constituents are strongly suspicious of government intervention and regulation.

The economic costs and benefits are equally mixed. Genetically modified corn and soybeans have greatly increased yields for his farming constituents, but have also led to restrictions on where they can sell their crops. Cloned animals could improve the overall value of a given herd with higher-quality meat. But I.M. knows from past experience that, when consumers are spooked about food safety, his constituents can get hurt economically. He remembers those who lost family land during the mad cow disease scare in the 1990s, because people were eating less beef and many countries refused to allow imports of U.S. beef.

I.M. knows he must make his decision with careful political reasoning but, as a member of St. John's, an ELCA congregation, he wonders what guidance his church might offer. He'd like to ask his pastor and fellow members what they think should be done, just to hear some voices from outside the normal channels. He is also curious what, if anything, the ELCA has said officially about these issues.

3: Cracking the Code of Life Segment 16: Contemplating the Message (use minute 1:44:15 to end) and choose one of the dilemmas posed there.

## **Toward a Lutheran ethic in the age of genetics**

The underlying question throughout this study has been: "What should this church teach with respect to the development and use of genetics that will be faithful and beneficial in the years ahead?" This session responds directly to that question by sketching out principles that can serve as guidelines for moral discernment in the age of genetics. As possible components of a moral vision, they do not provide a practical program of rules or answers for complex and challenging questions. They do, however, propose specific means to encourage the promise of genetics while still guarding against the dangers when evaluating new genetics developments as they unfold.

These proposals attempt to fill in some of the space between universal principles such as "love your neighbor," "seek justice," or "reduce suffering" and the practical decisions that must be made. As components for an ethic of faith active in love seeking justice, these principles are intended to serve as guides to wise deliberation, creative choices, careful practices, and informed decisions. These are not established principles or policy of the Evangelical Lutheran Church in America, but they are proposed here in order to explore their suitability for such a role. After they are explained in brief, you will be invited to test them out by discussing one of the real life stories above.

### **Shall we respect and enhance the integrity of life before God?**

The first directive is a sweeping one of the "first principle" kind, but it provides more specific guidance in the contemporary context than the basic directive "love your neighbor as you love yourself." This directive can be formulated as: *In all choices, efforts, and relations,*

Several definitions of the *precautionary principle* are in use and they vary in clarity and moral force. This study will use the following: "When human activities may lead to morally unacceptable harm that is scientifically plausible but uncertain, action shall be taken to avoid or diminish that harm."

*Christians should respect and enhance the integrity of life before God.*<sup>2</sup> It broadens and extends "love of the neighbor" to more than nearby individuals. It is directed to *all* life, human and nonhuman, and includes obligations to future generations of life. It implies that all of creation deserves attention as part of the moral community. It acknowledges that future life has some stake in the choices we make, for their integrity depends on the present.

This formulation depends upon several Christian commitments already discussed, beginning with the presumption that God values life and is at work to bring good for all life (Genesis 1:31, Romans 8:28). It assumes that Christians are called to participate in God's ongoing work. It also is sensitive to both the problem of sin and the call to anticipate the transformative reign of God. It addresses these by holding in tension the need to live in basic conformity with and consent to the givenness of life while still living critically and creatively (Isaiah 43:16-21; 2 Corinthians 5:11-21).

Placing respect first indicates that humans live first and foremost under the imperative to respect—to recognize and show regard for others and for one's self. The very presence of life makes a moral claim and establishes ethical constraints upon what can and should be done. Living creatures, as subjects of respect, cannot be treated solely as means to others' ends.

There is an analogy here to the wisdom of medical ethics. Medical ethics holds that in situations of uncertainty it places the admonition to "avoid harm" above "do the good." The integrity of life that medicine seeks to honor leads it first to counsel the avoidance of harm, even while encouraging attempts to proactively make the patient's situation better. Respect constitutes a moral baseline for all actions and relations.

The directive to enhance life calls for humans to enhance the *community* of life as well—to make it better. It suggests that Christians should work to aid life to be fruitful and multiply (Genesis 1:26-28) in all of its complexity insofar as that does not violate the demand of respect. This encourages the full use of human creativity and imagination to extend the potential knowledge and power given into human hands, but it specifies for what purpose: the integrity of life.

The determination of what must be "respected" and what may be "enhanced" requires careful reflection on the basis of principles such as those sketched in the previous session: sufficiency, sustainability, solidarity, and participation. But several additional principles may also aid us in determining how we might live with the potential tension between respect for life and the enhancement of life in relation to genetics.

### Shall we embrace a precautionary principle?

The tension between "respect" and "enhance" would seem to support the contemporary idea of the *precautionary principle*. ELCA social statements have not used this term, but they may be characterized as "cautionary" in tone because they are grounded in human responsibility for the care of creation and the future integrity of life. But what does the term mean and should it be used?

In 2005, a nine-person commission created by UNESCO completed a sophisticated and balanced study of precaution. They defined the principle at question as: "When human activities may lead to morally unacceptable harm that is scientifically plausible but uncertain, action shall be taken to avoid or diminish that harm." This definition covers only a limited class of risk-taking actions—but an exceedingly important one. To quote UNESCO, "The [precautionary principle] applies to a special class of problems that is characterized by: (1) complexity in the natural and social systems that govern the causal relationships between human activities and their consequences, and (2) unquantifiable scientific uncertainty in the characterization and assessment of hazards and risks. The existing decision-support tools to cope with risks in a rational way, such as probabilistic risk assessment and cost-benefit analysis, have limited value under these conditions."<sup>3</sup>

In short, this mediating principle would not apply to all genetic developments but rather comes into play only when existing tools for risk assessment are overwhelmed by a high level of uncertainty. It does not apply to standard risk-benefit analysis where good



and bad outcomes can be predicted and evaluated. Rather, it applies in cases of uncertainty, as determined by the science in question, when we do not know enough to say which actions will most likely produce the greatest good. For instance, cell phones may not be used while in flight because the possible consequences of multiple, various radio frequencies cannot be known for certain. It is uncertain whether they could interfere with the aircraft's functioning. Therefore, precaution is called for.

Such concerns do not place a "never" in the way of any form of development, but they do counsel restraint until sufficient cause and effect relationships are fully and safely established. This principle should not be seen as intending to stifle exploration, innovation, or new technology. It intends, rather, to encourage it, but with a note of caution and a concern for transparency that insists on well-informed public accountability. Some are asking then, for instance, if certain forms of genetic engineering operate under conditions uncertain enough to be subject at this time to the precautionary principle. The objection is not to such engineering in principle, but follows from limited knowledge about beneficial/harmful, short-term/long-term consequences. At this point, risks cannot be determined but scientific understanding can imagine plausible harms. Might not caution be in order?

### **Shall we consider long-term social and economic impact?**

In matters of regulating new products and processes, responsible government regulators and policymakers have historically relied on three standard criteria: (1) human safety, (2) global animal and environmental risk and safety, and (3) technological efficacy. Increasingly over recent decades, a fourth criterion has been proposed—*long-term social and economic impact*. This idea suggests that regulation of new products and processes take into account their likely social and economic impact over the long-term. Some have resisted this fourth factor by objecting, for instance, that it hinders development, violates global trade agreements, or is unscientific.<sup>4</sup>

The principles from the ELCA's economic life social statement explored in session three, however (sufficiency, sustainability, solidarity, and participation), suggest that, from a faith perspective, socio-economic criteria *should have some role* in evaluating genetic products and processes. This follows, as well, from the growing recognition that biotechnology, like all sciences, is not driven solely by the objective search for knowledge, and that the delivery of technology is not neutral and may have unintended consequences. Rather, biotechnology and the delivery of that technology are both significantly affected by social and economic structures and interests, and, in return, both dramatically shape these realities. For example, much of genetic research is done by for-profit companies. While the researchers no doubt want to improve the quality of human life and diminish human suffering, they also have to make their work profitable. This fact affects the directions of genetic research: what illnesses are combated, which drugs are developed, and who will likely benefit from whatever treatments are eventually approved.

Social and economic criteria belong on the table when developing national regulatory and product approval processes. The assessment of risks associated with agricultural biotechnology is a complex problem that cannot be undertaken only according to health impact or only according to objective scientific expertise.

It should be recognized that this principle requires the development of effective models to implement appropriate socio-economic assessment. This is, of course, a notable challenge to work out in the face of conflicting interests, and this is work that the church as church cannot adjudicate. It must call upon its laity with appropriate expertise to be involved in such determinations as a part of their vocational callings. Still, the church must insist that concerns of justice, social impact, and involvement of the broader public be included in models of risk assessment in the age of genetics.

### **Shall we encourage scientific progress for the sake of the Common Good?**

These legitimate concerns for caution are to be accompanied by the church's equally legitimate encouragement of the development of genetic knowledge and power. People of faith understand that human creativity, expressed in the developments of genetics, must

*Koinonia* is a time-honored Christian word drawn from the Greek of the New Testament and used widely in the early church. Its exact meaning cannot be captured by any one English word, but includes: "communion with," "mutuality," "fellowship," "mutual service," and "compassionate care." All of these meanings contribute something to the image of congregational life lifted up here.

be seen through the lens of this church's concerns for a just, sustainable, and healthy society. The church, then, will encourage individuals, corporations, and institutions to set public policy that will:

- maximize genetic information without discrimination;
- attend to global health issues and needs, whether they can be helped by genetic research or not;
- advocate that genetic research and discovery benefit the common good of all (meaning human beings, animals, plants, ecosystems around the world);
- affirm reasonable life extension and quality of life improvement without expecting or seeking immortality;
- encourage stem cell research and, if necessary, therapeutic cloning;
- encourage varieties of biotech research aimed at improving human health and well-being, while registering skeptical caution about enhancements that might lead us beyond the pale of what constitutes human personhood.

Through these commitments, this church will address social problems and can encourage the transformation of sorrows and suffering into solutions. These commitments would avoid making absolute the natural or social past or present by encouraging human participation in seeking new ways in which life may flourish.

A Lutheran ethic leads to creativity, not conformity. Creative attempts to make life better become anticipations, fragmentary yet authentic, of God's promise signaled in the resurrection. God's promise will not be realized by human achievement and God's kingdom will not come through genetics. Human achievements in respecting and enhancing life, however, are but fragmentary moments of health and goodness that witness in history to the ultimate victory of God that is to come.

### Shall we live into new forms of Christian *koinonia*?

The principles just discussed are largely about social and policy guidance. But other dimensions of a moral vision must be addressed, including the character of Christian community. The realization of Christian *koinonia* is a value worth seeking.

Christian care for fellow Christians is grounded in God's grace to all of us, even though, because of sin, none of us can be thought to truly deserve it. God's love is the model and motivation for loving others in the Christian community (John 13:31-35), and a *koinonia*, *mutuality* or *communion of care* has always been a value in the Christian community. Christian *koinonia* today, however, encourages Christian care in a new key when lives are often marked by ambiguities, disappointments, and uncertainties in relation to developments in genetic medicine, business, and agricultural enterprises. The choices Christians must make might well increase the ambiguity and complexities that the Christian community must learn to live with. Christian choices will sometimes disrupt the assumptions of shared viewpoints and common values. The special challenge today, then, in loving others in the Christian community, will be to grant respect and provide care to the brother or sister with whom I disagree sharply or whose choices have taken them on a different path (Romans 12:9-21).

Christian *koinonia*, as understood today, can be envisioned as the possibility of brothers and sisters joining together around the table of Christ's Supper despite honest disagreement and diverse paths. At the table will be parents who have decided to end a pregnancy for genetic reasons along with the single mom who has chosen to bear her baby to term. There will be a lawyer, an insurance executive, and a research geneticist standing next to a man anxious about whether a gene marker will cost him his job and a teenager who has just discovered that he is a candidate for an early heart attack. Around the table of Christ, there will be those on both sides of a public policy issue that is dividing their city, two farm families who disagree vehemently on transgenic seeds and organic farming. A communion of care means that these individuals accept and support one another as they have

each been accepted and supported by the body and blood of Christ received in, with, and under bread and wine.

Such mutuality is not just a toleration of difference for it means Christians will seek to discern together God's guidance, and this may include respectfully challenging each other to think and choose differently. It does, however, recognize that, in increasingly complicated and complex situations, the will of God may not be absolutely clear, even while it is absolutely clear that the will of God must be sought (Romans 12:1-2). Such Christian discernment involves seeking to know when challenge and action are needed and when acceptance or accompaniment are called for.

The reality of Christian *koinonia* today reminds us of what may be called the *accompaniment* side of ethics. Ethics and morality are often identified with taking action and making changes, but we must recognize that in some situations there is nothing to be done, no change to be made. This becomes clear, for example, at the bedside of a dying loved one. There is little or nothing that can be changed, nothing to be done except to be present to that loved one. A communion of care today will mean finding ways to befriend the brother or sister by accompanying them when change is not possible. It will be marked, sometimes, by finding constructive ways to simply help each other cope. It will re-image together what the future looks like, because some things cannot be changed or removed. This simple accompaniment, this "doing little," can be the most difficult kind of care.

Christian *koinonia* is an ancient concept but it carries new dimensions today. In every case Christian *koinonia* means mutuality. It happens when discernment is shared in mutual study, even if conclusions are not uniform. It happens when members cope together and wait together and re-imagine the future together because their sorrow cannot be removed. It happens when all receive the ministry and the preaching of a pastor who is servant to all of them despite their diversity. Such a communion of care is a vital Christian identity to be lived into in the age of genetics, and it is possible by the power received from Christ who is the real Host of the sacramental meal.

## Conclusion—redeemed decision makers

Stepping up to responsibility in an age of genetics is not easy work, but it is God's calling to us. It is a call that should be accepted with our eyes open to human finitude and possible failure but also with our eyes open to hope and the benefits for life that may come from genetics. Genetics is a powerful and ambiguous blessing. We must remember that all options are not equally valid and that choosing between moral goods is not unimportant—such is the nature of our responsibility.

Christian responsibility begins by recognizing that God has endowed us with the freedom and power to make decisions, but without the possibility of seeing all possible contingencies or being able to guarantee the outcomes. It is an unavoidable fact of life in the age of genetics that we must make difficult choices without full knowledge, and when so much potential and harm hangs in the balance. Oftentimes this will mean not just trying to distinguish good from evil, but having to choose between competing goods. Such competing claims cannot be equally validated in a single decision, and the fact is we will often find ourselves making choices where the outcomes are irreversible. This is daunting.

Accepting such responsibility in faith is what makes it an adventure and a possibility, but we are not alone as we do so. God has made us, redeemed us, continues to care for us, and will finish making all things new. As responsible agents, we will be creative and sometimes bewildered. We will always be limited. We will be both successful and misdirected. But in all this we are also redeemed decision makers. This is the Christian assurance that runs from the beginning and to the end of faith and responsibility in the age of genetics.

## Invitation to conversation, prayer, and action

Imagine yourself as one of the individuals in the real life story you read at the beginning of the session. It is true that we can never know just what we would do in a situation

until we actually face it. Still, imagining ourselves as one of the participants in these stories can bring us close to concrete realities. Each of the stories are based on genuine incidents, even though the names and situations have been altered enough to safeguard those originally involved. All represent challenges that must be faced in the age of genetics.

As you imagine yourself in one of these situations draw upon what you have learned and discussed in the previous sessions, and draw especially upon the principles offered above. This is a good way to test whether these principles are faithful to the Christian faith and helpful aids for making real-life decisions. As you deliberate, then, consider not just “What would I do and why?”, but also “What should our church be teaching?”



### Questions to use:

- Which individual did you identify with most closely in this situation?
- What would you do or what would be your counsel as to what should be done?
- Which principles suggested in this session seemed especially valuable as you tried to think about what to do? Why?
- What additional kinds of principles would you use or need if you were in this situation?
- **Action question: What is your response to this study on genetics so far? Please take the time to fill out the response form found on page 111 in order to share your feedback with the task force that will guide the ELCA effort to shape a social statement on genetics.** (Please remember to take some time to look at the topical sessions in Part B, if you have not already!)

### Closing prayer

#### Invitation to intercessory prayer

Pray for those who serve on ethics boards, government advisory councils and all who seek wisdom in making difficult decisions about the future of genetic developments.

#### Praying with the tradition

O God, you made us in your own image and redeemed us through Jesus your Son. Look with compassion on the whole human family; take away the arrogance and hatred which infect our hearts; break down the wall that separate us; unite us in bonds of love; and, through our struggle and confusion, work to accomplish your purposes on earth; that, in your good time, all nations and races may serve you around your heavenly throne; through Jesus Christ our Lord. Amen.

(*Lutheran Book of Worship*, page 44)

### Endnotes

1 The facts from the FDA report and quoted responses to it are taken from the January 15, 2008 story as report at <http://edition.cnn.com/2008/HEALTH/01/15/fda.cloning/index.html>. The individuals, the “proposed” bill, and the framing of the issues have been imagined specifically for this case study.

2 Adapted from Per Anderson, “Sufficient, Sustainable Lifespan for All: Responsible Biotechnology and ELCA Social Thought” in *Theological Foundations in an Age of Biological Intervention*, David C. Ratke, Editor. (Lutheran University Press, 2007). This normative formulation is directed here toward this study’s own purposes, but it appreciates and bears family resemblance to the work of William Schweiker, as suggested in the Anderson essay. Schweiker’s formulation and program represent a somewhat different and much larger agenda than this study and those familiar with his work will recognize the differences.

3 See United Nations Educational, Scientific and Cultural Organization [UNESCO], World Commission on the Ethics of Scientific Knowledge and Technology, *The Precautionary Principle*, (Paris, March 2005), 16.

4 William B. Lacy. “Agricultural Biotechnology, Socioeconomic Issues, and the Fourth Criterion.” (pp. 77-89) in *Encyclopedia of Ethical, Legal, and Policy Issues in Biotechnology*. Thomas J. Murray and Maxwell J. Mehlman, editors. (John Wiley & Sons, Inc., 2000).

# Part B: Exploring Responsibilities and Engaging Issues







# Genetics and Congregations: What should we do?

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

Good and gracious God, giver of all good gifts, we give you thanks for the gift of your Word, of each other, and for your Church. As we seek to understand, give us wisdom and patience. Help us to listen thoughtfully with profound respect for one another. Instill us with vision and imagination, humility and forgiveness. In Christ's name we pray. Amen.



### HEARING THE WORD

Ephesians 4:1-15

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

This session encourages conversation on how congregations might address genetics or genetics technology issues today. We must be prepared to understand enough of the science and to listen to the potential implications posed by the application of genetics and biotechnology in order to consider how we, as Christians, might respond to the questions. Within congregations are families affected by the chronic nature of genetic conditions, people living in the midst of biotechnology they had no idea would impact their lives, and people called to advocacy for change because of their belief that in God's kingdom life should be different.



### Real life stories

As you read these stories, ask yourself: What could our congregation do?

#### 1. Belinda and Cody

Amalaya and Zach are truly enchanted. It seems like just yesterday that Belinda was born, beautiful with all that dark hair. Maybe it was just yesterday. Everyone in the hospital is worried and won't let her go home, but she is just a little slow to eat. She is so cuddly. They keep saying something about low muscle tone—how would you feel after a two-day labor. No wonder she seems floppy, she will perk-up soon. Just wait until she meets Cody. Already at six weeks he is holding his head up and looking right at his mother! What luck to have a best friend with a baby at the same time as you!

Nine months later...

Amalaya and Zach now have confirmation that Belinda has SMA, spinal muscular atrophy. She has been sitting on her own but has lagged behind Cody. Still, her eyes flash and she giggles and laughs and babbles all the time. Somehow that makes some of this bearable. How could she have SMA? No one in the family has had anything like this. Amalaya and Zach learn that they each carry a hidden recessive gene and have a chance (actually 25% chance) that future children will have SMA.



In this passage, the image of Christ rising and giving grace as a gift (Eph. 4:8-9) comes from Psalm 68:17-20, a hymn of praise as the Lord God ascends the holy mountain, receiving gifts from people and giving the gift of salvation.

How has Christ's gift of grace strengthened you to keep the unity of the Spirit in the bond of peace? (Eph. 4:3)

Spinal muscular atrophy is a disorder that affects the control of muscle movement. It is caused by a loss of specialized nerve cells, called motor neurons, in the spinal cord and the part of the brain that is connected to the spinal cord (the brainstem). The loss of motor neurons leads to weakness and shrinkage (atrophy) of muscles used for activities such as crawling, walking, sitting up, and controlling head movement. The condition progressively worsens with time.

Alpha-1 antitrypsin deficiency is caused by the lack of a liver protein that blocks the destructive effects of certain enzymes. The condition may lead to emphysema and liver disease, and, in rare cases, skin disease..

Five years later...

Cody is headed off to kindergarten! Belinda has already been “going to school,” first as part of the birth-to-three program and later in the preschool program for children with special needs. The house is finally completely wheelchair accessible. What a challenge! Next project is the church! Zach’s sister is asking about the genetics of SMA. She and her husband are expecting and her OB asked if she wanted prenatal diagnosis for SMA. There is screening to identify carriers of SMA. Who would want to know that during the pregnancy?

Twelve years later...

What a difficult weekend! Cody is graduating from high school. Does anyone remember that Belinda should be graduating, too? Is it five years already since Belinda succumbed to pneumonia? It seems like yesterday. At least no one else in the family has had to endure such lasting pain.

## 2. Transgenic Seed

The Smiths and Joneses are both members of Rural Small Town Lutheran Church. Mr. and Mrs. Smith live on an acre of land in the country with their two children. They both have full time off-farm employment. One of the children, Bobby, has severe food allergies that can be exacerbated by hidden ingredients in processed food. In an attempt to reduce the chance for reactions, they have cultivated a large organic garden. They use the produce fresh, as well as can and freeze it. They also installed special air filters and placed wood floors throughout the house. Bobby has had fewer reactions over the past year and they are thrilled.

Mr. and Mrs. Jones live across the road from the Smiths. They also have two children, and run a good sized commercial grain farm with a modest livestock operation that keeps them both busy nearly year around. They have no employees except for a retired farmer who occasionally helps during planting and harvest. One of the children, Jenny, has a severe disability. Their budget is severely strained by the costs of giving Jenny the best care and providing her with opportunities for a productive future. They really can’t imagine doing any less for Jenny.

The field representative of Shoots and Roots (a fictional company) has offered the Joneses the opportunity to raise genetically modified (GM) seed, which would provide an additional \$6,000 a year with little additional cost.

Joe Smith hears about GM seed next door and is livid. Will pollen from the GM crops reach their garden and contaminate their plants? How can he know that his produce is safe and won’t lead to allergic reactions for Bobby?

## 3. Insurance Fears Lead Many to Shun DNA Tests

Victoria Grove wanted to find out if she was destined to develop the form of emphysema that ran in her family, but she did not want to ask her doctor for the DNA test that would tell her. She worried that she might not be able to get health insurance, or even a job, if a genetic predisposition showed up in her medical records, especially since treatment for the condition, alpha-1 antitrypsin deficiency, could cost over \$100,000 a year. Instead, Victoria sought out a service that sent a test kit to her home and returned the results directly to her.

Victoria did not tell her doctor when the test revealed that she was virtually certain to get emphysema. Knowing that she could sustain permanent lung damage without immediate treatment for her bouts of pneumonia, she made sure to visit her clinic at the first sign of infection. But then came the day when the nurse who listened to her lungs decided she just had a cold. Ms. Grove begged for a chest x-ray. The nurse did not think it was necessary.

“It was just an ongoing battle with myself,” recalled Ms. Grove, of Woodbury, Minnesota. “Should I tell them now or wait till I’m sicker?”

## Genetics in your congregation

Confirmation of DNA as the potential unit of inheritance (heredity) was published in 1953. In the fifty plus years since the first publication of the double helix structure of DNA, increasing knowledge of heredity has enabled changes in almost every aspect of our lives. The information has grown so dramatically and so quickly that people within the various genetics disciplines can hardly keep up with all the latest advances. For those who went to school before DNA had been identified, before the number of chromosomes was known or before we could visualize genes and genetic manipulation, all this fuss about genetics doesn't seem worth the effort. It is too complex to matter. Many who did learn about genetics in school find the subject fascinating, but the details daunting. The lack of a fundamental knowledge of genetics information is a major barrier to any discussion of genetics and the new technologies it offers. Christians need to become genetically literate in order to understand and respond. We are called to responsible participation in genetic decision-making, both in personal and societal realms. This level of active involvement requires preparation.

So what do we need to do to understand more about genetics and new technologies? The easiest place to start may be to search out stories in your own congregation. Are there farmers in the congregation faced with the choice about whether or not to use genetically modified seed? Are there members of your congregation who work with DNA in research and development projects either at a local university or in a commercial lab? Are there members of your congregation with a disability or birth defect? Could members of the congregation who have been pregnant tell about their experience with the offer of genetic screening during the pregnancy? Are there people in the congregation who advocate for increased social services for those with cognitive disabilities? The number of people in your congregation involved with genetics and biotechnology will likely surprise you.

Stories from people you know, as well as the stories in the beginning of this session, can help your congregation both focus on the topics and personalize the issues. If Sally has diabetes at age fifteen, what can the youth group do to support her participation in events that are often centered on food? Could a community physician come to talk about diabetes, but also talk about the promise of stem cells together with the challenges in their use? John, who farms acres of corn and has for twenty years, may not fully realize the issues with GM corn and global corn distribution. Could your synod office connect him with a rural ministry or global ministry advocate who could help him understand the issues?

Congregational members who have expertise in genetics and biotechnology can help the congregation understand the changes, good or bad, in people's lives related to developments in genetics. It should be noted, however, that at times the work of these experts may be questioned simply because of what they do. For example, scientists who work with mice in order to better understand how the same gene operates in a human might be labeled as cruel to animals, even though he or she is doing the work with a passion to help cure disease.

As a church, we believe that Christians live out their call and God's claim on their lives in a variety of vocations. New opportunities made available through genetics technologies—such as genetically modified crops or genetic testing—have been developed and are being applied by individuals who, in many cases, understand their work in genetics to be a response to God's vocational call. Many of these people desire to discuss the ethical implications of the work they do through the lens of their faith. The congregation (and pastors) can provide a forum for them to do just that.

As a church we also recognize that the fruits of medical research and innovation are often means through which God blesses and heals creation. It commends the important work of medical research and supports investment in its goals of healing afflictions, relieving human suffering, and promoting wellbeing. We also affirm the important service to God and neighbor rendered by those who develop and use curative technologies and practices.<sup>2</sup> Many congregations have members who work in these fields and who can help congregational members understand the complicated science of, and moral issues

The Genetic Information Nondiscrimination Act of 2008, also referred to as GINA, is a new federal law that protects Americans from being treated unfairly because of differences in their DNA that may affect their health. The new law prevents discrimination by health insurers and employers. The President signed the act into federal law on May 21, 2008. The parts of the law relating to health insurers will take effect by May 2009, and those relating to employers will take effect by November 2009.

surrounding, genetics. A firm understanding of both the science and the moral issues involved will help Christians address such questions as: How should we think about genetics research and application in light of our Christian teachings and beliefs? How do we show love of our neighbor in this new context? Who is our neighbor with regard to this new technology?

True dialogue depends upon informed participants who are willing to discuss all the implications of the choices being considered. In the past, such openness has not always been experienced between the faith community and the scientific community. Scientists, pastors, and theologians need to openly and respectfully engage each other about the moral implications of genetics, and then share their conversations with the congregations. Pastors, congregational members, and experts from either within or outside the congregation can work together to enable meaningful public discussion of these important issues.

It is particularly important that congregations support educational opportunities for pastors to learn about issues surrounding genetics research, development, and the use of new technologies so that they can be effective in providing pastoral care for individuals and families whose lives are impacted by genetics.

Congregations may also engage in advocacy to provide support where needed, to influence policy decisions, to push for responsible legislation, or simply to focus attention on key and challenging issues. Religious groups have long been identified with advocacy related to easing poverty, eliminating hunger, and achieving justice and human dignity. Advocacy regarding genetics issues has included many topics such as embryonic stem cell therapy, insurance discrimination, access to genetics services, and genetic testing. Advocacy in and of itself does not imply either a conservative or liberal position.

Developments in genetics science and technology also lead to questions about the regulation of genetics research and use via legislation. As an example, we can cite the new federal legislation called GINA, the Genetic Information Nondiscrimination Act.

Regulation affects both business and individual choices. How much and what kind of regulation should government exercise over the ways biotech businesses operate? What are the criteria that justify government regulation? Should the market be largely unregulated in order to encourage the development of profitable genetic technologies? Is it legitimate for religious institutions to adopt an official stance on public policy issues and advocate for specific pieces of legislation. What are the criteria that justify doing so? What kinds of legislation? Should the church take a public position with formal statements, and devote resources to legislative advocacy?

Three observations can be made regarding genetics developments and public policy. First, while there is general agreement that the moral and ethical principles (such as those described in sessions A4 and A5) should be used to shape public policy, there isn't agreement about how those principles should be applied to protect or regulate groups in our society. Second, public policy often seeks a position that is least offensive to the most people—the lowest common denominator—which may not promote the common good. Finally, the speed at which genetics technology is advancing means that the public policy of today almost certainly will not address the realities of tomorrow.

## Resources for your congregation

We have only touched the surface of the challenges that the age of genetics brings to people of faith. Clearly, Christian congregations have important but complex responsibilities and ministries to sort out. What are the resources available within our congregation that can assist us in public discussion, moral deliberation and discernment, and action in the new context created by genetics science and technology? In what follows, we will answer this question by highlighting resources that were presented in more detail in sessions A4 and A5. If you missed those sessions, you are encouraged to take a few minutes to read through them.

## Scripture

Our greatest resource is always scripture. Christian discussion and action with respect to social issues are grounded in the double love commandment: “You shall love the Lord your God with all your heart, and with all your soul, and with all your mind.... You shall love your neighbor as yourself.” (Matthew 22:37, 39). Love and justice are the “red thread” that runs throughout the Bible. Much of scripture “unpacks” this double love commandment and provides guidance for people of faith as they seek to live responsibly in accordance with God’s will in frequently complex and morally ambiguous circumstances. Scriptural teaching on creation and the care of creation also grounds Christian moral discernment and action. The Bible’s emphasis on human sinfulness and finitude add realism to Christian ethics. And the Bible’s teaching on redemption and salvation ground Christian hope and optimism in addressing seemingly intractable moral issues.

## Congregations as communities of moral deliberation

The first social statement of the ELCA, *Church in Society: A Lutheran Perspective*, describes the church as a community of moral deliberation. The church seeks to “discern what is the will of God—what is good and acceptable and perfect” (Romans 12:2). Deliberation in the church gives attention both to God’s Word and God’s world, and to the relationship between them.

The church can provide a safe place for moral deliberation and discernment because we are a people united in Christ. True ethical deliberation will result in the expression of diverse perspectives; in the Christian community of faith we can leave partisanship at the doors of the church. This then raises the question whether such a commitment to honest give and take should stay inside the church doors. The answer is no. As a community of moral deliberation, the church seeks to engage those outside the church in discernment and action that leads to the common good. This larger engagement is critical with respect to matters of genetics and biotechnology.

## Established principles to guide ethical deliberation

The ELCA is committed to certain principles to help guide our moral deliberation. For example, four principles—participation, solidarity, sufficiency, and sustainability—are clearly visible in three ELCA social statements (those on the environment, peace, and economic life) that address similar concerns to those that might be addressed in a social statement on genetics.<sup>3</sup> These four principles (which are detailed in session A4) help to articulate a core ethics of “faith active in love through justice” for ELCA social policy.

The principles of sufficiency, sustainability, solidarity, and participation *should* have *some* role in evaluating genetic products and processes for they point to the reality that genetics research and technology are significantly affected by social and economic structures and interests that may not have the “common good” in mind. These principles affirm that the wellbeing of the most vulnerable locally and globally must be protected and promoted. The church is responsible to see that the concerns of justice, social and environmental impact, and involvement of the broader public are included when decisions are made with respect to (1) areas of genetics research, (2) the delivery and use of genetics technology, (3) genetics related policymaking, and (4) government regulation of genetics related businesses.

## Considering another principle

One contemporary idea that may also be worthwhile to consider is the *precautionary principle*. This principle has been defined by UNESCO as “When human activities may lead to morally unacceptable harm that is scientifically plausible but uncertain, action shall be taken to avoid or diminish that harm.”<sup>4</sup> The precautionary principle has to do with issues of risk assessment, and asserts that, when there are too many “unknowns” and “uncertainties” to adequately assess the risks of particular lines of research or technology use, caution is called for. Indeed, the level of uncertainty as to whether or not “morally unacceptable harm” may be caused by particular human activities may be sufficient reason to avoid those activities—at least for the time being until the level of uncertainty is sufficiently lowered.



It should be noted that just because we don't know the outcomes and can't properly assess the risk doesn't automatically place a "never" in the way of any form of development. The precautionary principle supports restraint *until* sufficient cause and effect relationships are fully and safely established.

### Congregation as Community: Christian Koinonia

*Koinonia* is an ancient Christian word drawn from the Greek of the New Testament and used widely in the early church. It can be variously translated as "communion with," "fellowship," "mutual service," and "compassionate care." It points to an understanding of the church as a community of mutual care.

Mutual care in the body of Christ (the Church) is grounded in God's grace and Christ's command: "I give you a new commandment, that you love one another. Just as I have loved you, you also should love one another. By this everyone will know that you are my disciples, if you have love for one another" (John 13:34-35).

*Koinonia*, the vision of the church as a community of mutual care, may often seem elusive, but it is a vision well worth seeking to realize, even if human sinfulness means it will not be realized perfectly. The degree to which we truly care for each other—often in spite of disagreements—is the degree to which we will be able to creatively confront and struggle through the complex challenges we face together in the age of genetics.

### Invitation to conversation, prayer, and action



#### QUESTIONS FOR DISCUSSION

- In what concrete ways do we as a congregation enable each and every member, including those with physical disabilities, chronic illnesses, mental illnesses, or cognitive disabilities, to become fully involved in the ministry of this church? Would Belinda be able to navigate in her wheelchair in your church facility?
- How might congregational members on different sides of genetics-related issues talk with each other? In the second story what does Christian *Koinonia* look like?
- In our individualized and privacy-conscious society, the state of our health or illness is considered "for your healthcare providers' eyes only." How much does one share? With whom? How do we as pastors and congregational members provide support, but honor privacy?
- What are the unique contributions that pastors can provide when addressing ethical questions? What do pastors need to know to provide spiritual help and guidance concerning the options available through genetics technologies?
- What are the connections and resources in our congregation with the field of genetics and genetics technology?

#### Which of the following are actions that our congregation could take?

Provide members with education about genetics along with opportunities for deliberation and advocacy on issues specifically related to the ethical choices presented by new genetics technology.

Seek ways to encourage involvement in church life by those who are affected by genetic conditions.

Strengthen efforts to meet the spiritual and social needs of people facing life-long chronic illness or disability.

Advocate for access to social services that address special educational needs, specialized care requirements, and respite care for families with children who have special healthcare needs (often conditions that have a genetic basis or contribution).



Ensure that all paid staff of the congregation have access to services that provide thorough and accurate genetics information.

## **Closing prayers**

### **INVITATION TO INTERCESSORY PRAYER**

Pray for parents who are struggling to make right decisions, for congregations wanting to do what is supportive, and for pastoral care providers.

### **PRAYING WITH THE TRADITION**

Almighty God, who has given us grace at this time with one accord to make our common supplication to you, and has promised through your well-beloved Son that when two or three are gathered in his name you will be in the midst of them: Fulfill now, O Lord, the desires and petitions of your servants as may be best for us; granting in this world knowledge of your truth and in the world to come life everlasting. Amen

(Prayer of John Chrysostom, who lived 347 to 407)

## **Resources**

### **ELCA Advocacy**

[www.elca.org/advocacy](http://www.elca.org/advocacy)

### **ELCA Disabilities Ministries**

[www.elca.org/Growing-In-Faith/Ministry/Disability-Ministries.aspx](http://www.elca.org/Growing-In-Faith/Ministry/Disability-Ministries.aspx)

**Genetics and Public Policy Center** [www.dnapolicy.org/news.eneews.php?action=detail2&newsletter\\_id=22](http://www.dnapolicy.org/news.eneews.php?action=detail2&newsletter_id=22)

**Genetic Alliance** [www.geneticalliance.org/](http://www.geneticalliance.org/) An organization of organizations concerned about genetic conditions and genetics-related advocacy.

## **Endnotes**

- 1 Excerpted and adapted from February 24, 2008 By AMY HARMON *New York Times*
- 2 These ideas are evident in *Caring for Health: Our Shared Endeavor*, Evangelical Lutheran Church in America, adopted at the Churchwide Assembly, August 15, 2003.
- 3 *Caring for Creation: Vision, Hope, and Justice*, Evangelical Lutheran Church in America, adopted at the Churchwide Assembly, August 23, 1993; *For Peace in God's World*, Evangelical Lutheran Church in America, adopted at the Churchwide Assembly, August 20, 1995; *Sufficient, Sustainable Livelihood for All*, Evangelical Lutheran Church in America, adopted at the Churchwide Assembly, August 20, 1999.
- 4 UNESCO, 25.



# Genetics and Human Identity: Who are we, really?

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

Holy Wisdom, giver of all life and source of all creating, we give you thanks that your Spirit moves throughout the world, transforming us, and calling us to you. In faith and trust we bring to you our uncertainties, our fears, our questions, and our hopes. Free us in Christ for service to our neighbor as we dwell in your Word and listen for your Spirit. Guide us, we pray, in Christ's name. Amen.



### HEARING THE WORD

Romans 5:12-21

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

Each of us was given a genome at birth—that is, we were given a specific sequence of DNA with a specific collection of genes. This collection of genes or genotype largely, though not exclusively, determines our phenotype (our body). Our genotype may also significantly influence our patterns of behavior. As Christians, should we consider our genome to be our essence? Is the answer to “who we are” found in the genome? Can we reduce the most sublime of our intuitions to gene expression? Are we so determined by our inherited genetic makeup that what we take to be daily freedom is a delusion? Do our genes lead us to sin? Can God's grace work through gene expression? If we answer affirmatively to these queries, then would scientists who alter our genomes be “playing God”? These are the kinds of questions about human identity discussed in this session.



### Real life story

Alice found it hard to believe the changes in the last seven years. Raised by an alcoholic and abusive single mother, at sixteen she ran away and eventually ended up living on the street. Befriended by a homeless man who preached on street corners and claimed to hear God speaking to him, she felt a measure of security. However, after being assaulted too many times, and when she discovered she was pregnant, she fled to a homeless shelter run by local churches.

Through the caring and generosity of the volunteers at the shelter she was able to receive prenatal care and got on the WIC program. She quit smoking and enrolled in a program to get her GED. By the time her baby boy, Bryce, was born, she was living in transitional housing, was working as a teacher's aide at a child development center, and had met a wonderful young man from the Lutheran church that ran the center. Two years later she and Bryce were baptized Lutherans and she married Jesse who adopted Bryce. Life was perfect—everything she had wanted and needed as a child she could provide for her little



The Hebrew meaning for “Adam” is “the earth creature,” which is a reference to all humanity (Genesis 2:1-25). When St. Paul uses “Adam” (Romans 5:14), he is using it in that sense. He also uses the Greek word for “human being” to describe Adam and Christ, so as to make clear that the earth creature's sin was not just the sin of one individual, but of a class of creation—an anti-type of the Coming One, the Messiah (Romans 5:14). The reader may choose to substitute “human” rather than “man” in Romans 5:12, 15-19 to make this point clearer.

How do you experience sin reigning over you because of death? How is that different from grace reigning over you through righteousness unto eternal life through Christ (Romans 5:21)?

guy.

Having worked at the developmental center for several years, she became concerned that Bryce seemed to be developing slower than the other kids. In particular, his speech was limited and very difficult to understand. One day, Alice mentioned these concerns to the developmental specialist at the center. She gave Alice the name of a developmental pediatrician and made an appointment for Bryce. At the end of the visit, the pediatrician sat down next to Alice and said that she was very concerned that Bryce might have a genetic condition called Velo-Cardio-Facial syndrome (VCF) that is caused by a missing piece of chromosome 22.

The next months were a blur with appointment after appointment. The chromosome test confirmed the doctor's suspicion. Finally, the day came to see the geneticist. He seemed very interested in the family history. Alice felt embarrassed because she didn't know much about her family. How could she possibly tell this doctor about Bryce's father? Before she knew it, Jesse told the geneticist that he wasn't Bryce's father and then Alice began telling him about the street preacher and his visions.

After a moment of silence the geneticist said, "I am willing to bet Bryce's father had VCF. Schizophrenia is more common in people with this specific chromosome problem. That would explain his visions—they were probably auditory and visual hallucinations." Her world collapsed. Is my baby going to end up on the street listening to and seeing things that aren't real? Is he going to be moving from shelter to shelter, rousted by the cops, ignored by people walking by, invisible? Jesse is going to hate me. How could I have brought this problem into our family? What are we going to do?

## Who are we, biblically speaking?

Who are we as human beings? The Bible gives us the basics. Each human being is a creature living in the tension between soil and spirit: "then the LORD God formed an earth creature from the dust of the ground, and breathed into its nostrils the breath of life; and the earth creature became a living being" (Genesis 2:7). On the one hand, we are soil, dust, dirt, ground, earth. On the other hand, with God's spirit, we envision rising to heaven, transcending the earth. On the one hand, everything we eat derives originally from the dust of the earth; and many, if not most, of the genes in our DNA we share with the animals and plants. On the other hand, our airplanes wing above the clouds, our minds ferry our imaginations into the outer reaches of space, and our spirits cultivate a thirst for life with the angels and unity with God.

Will the genetic revolution eliminate this tension? Will we cut off our transcendent yearnings? Will we resign ourselves to spiritless soil, to DNA and dust? When we ask the Old Testament to help us understand who we are, we find ourselves drawn toward the angels. In Psalm 8:1-9, we find that God created human beings just a little lower than the citizens of heaven. This passage complements the decisive text about humankind's creation in the image of God: "Then God said, 'Let us make humankind in our image [*tselem, icon, imago*], according to our likeness [*demuth, homoiousias, similitudo*]; and let them have dominion over the fish of the sea, and over the birds of the air, and over the cattle, and over all the wild animals of the earth, and over every creeping thing that creeps upon the earth'" (Genesis 1:26). This passage can prompt our curiosity. Just what is it about us that marks God's image? The original Hebrew does not help us because the terms *tselem* and *demuth* seem to suggest that we are a physical representation. But since God is not just an overgrown human being, it is less than clear just how we represent God in our bodies.

Jesus Christ represents God in his body. He is God incarnate. According to St. Paul, Christ "is the image of the invisible God, the firstborn of all creation" (Colossians 1:15). Christ is the image of God. He is also the image of who we are; or, more precisely, who we will become by the Spirit's power. Christ is the new Adam, the new human being, a model for all men and women. 1 Corinthians 15:45-47 observes: "Thus it is written, 'The first human, Adam, became a living being'; the last Adam became a life-giving spirit. But it is not the spiritual that is first, but the physical, and then the spiritual. The first human was

from the earth, a creature of dust; the second human is from heaven.” Even though Adam and Eve predate Jesus Christ, the latter takes precedence. Christ provides the defining images of the human race in relation to heaven, in relation to God. Adam and Eve anticipate Christ; Christ provides the definition of what is truly human.

Who we are in Christ includes more than just our physical makeup, more than the dust of the earth. It includes our redemption. Romans 5:17-18 contends: “If, because of the one person’s trespass, death exercised dominion through that one, much more surely will those who receive the abundance of grace and the free gift of righteousness exercise dominion in life through the one person, Jesus Christ. Therefore just as one person’s trespass led to condemnation for all, so one person’s act of righteousness leads to justification and life for all.”

Biblically speaking, then, is our identity determined by what we have biologically inherited? Jesus’ teaching suggests “no.” In a discourse in Mark about his mother and his siblings, Jesus speaks to another identity: “Then his mother and his brothers came; and standing outside, they sent to him and called him. A crowd was sitting around him; And he replied, “Who are my mother and my brothers?” And looking at those who sat around him, he said, “Here are my mother and my brothers! Whoever does the will of God is my brother and sister and mother” (Mark 3:31-35). Who we are in relation to God is not determined by our genetic inheritance.

One more biblical consideration needs mentioning here, namely, sin. When we turn to a founding document of our Lutheran tradition, the Augsburg Confession, we remind ourselves of our estrangement from God, of the distortion that contaminates the image of God associated with us. “Since the fall of Adam, all human beings who are propagated according to nature are born with sin, that is, without fear of God, without trust in God, and with concupiscence.” Now, in the age of genetics, we need to ask: is our propensity for concupiscence and our lack of trust in God due to our inherited DNA? Is our body estranged from God, so that we look for our Christ-likeness and our redemption not in the body but rather in the spirit? Is there an unbridgeable split between soil and spirit? Or might God’s spirit and God’s grace be at work in our DNA as well?

## Is it all in the genes?

When Christians grapple with interpreting science in light of our faith, we need to discriminate between what can be known in the strictly scientific sense and the myths which surround science. Yes, modern people can indeed believe in myths, even science myths! “Myth” here refers to a framework of assumptions or beliefs that surround science but which themselves are not scientifically demonstrated. Like a mitten on a hand, in our culture, the sciences dealing with our genes are surrounded by what can be called a “gene myth.” It is important to grasp the difference between the hand and the mitten, between what we can know scientifically and the gene myth.

According to the gene myth alive in our culture, “it’s all in the genes.” According to this mythical framework, our genome is the “blueprint” of what makes us human, the essence of who we are. To say “it’s all in the genes” fosters belief in *genetic determinism*, even genetic essentialism. What does this mean? Consider three ways in which the gene myth influences the way we interpret the advance of genetic science. First, *puppet determinism* is the assumption that our genome dictates who we are and what we do. Like a puppet dancing on strings, we dance on genetic strings. Accordingly, our genotype (genetic code) determines our phenotype (our body) along with our intelligence, emotional states, potential for professional success, inclination toward moral or immoral behavior, what kind of person we will eventually marry, and whether we will vote as a Democrat or Republican.

The second form of determinism is *promethean determinism*, which places human ingenuity into the driver’s seat. It capitalizes on the technological imperative, described in an earlier session. If our genetic code has the puppet power to determine who we are, so the logic goes, then perhaps our scientists can turn us into the puppeteers. Perhaps we can design the genomes of our own babies, bringing to birth the “perfect child,” so to

speak. On a broader scale, if our scientists can take control of our genes, we will be able to determine the future of the human race. If our laboratory scientists could get into the human genome with their wrenches and screwdrivers and rearrange our DNA, then we could determine the quality of human life that will prevail in future generations. We in the present generation may have inherited our DNA from our evolutionary history; but now we will take the power of nature into our own hands and guide the next phase of human evolution.

Promethean determinism may frighten us more than puppet determinism. We fear the *hubris* or pride of unbridled scientific advance that may lead to catastrophe. This fear leads to the third of the gene myth beliefs, namely, the commandment against *playing God*. We fear that if our scientists dig into our DNA with their wrenches and screwdrivers, they will make mistakes. These mistakes could become dreadfully damaging. Perhaps our scientists will accidentally alter the delicate balance of genetic systems, and this will cause a devastating genetic malfunction. Perhaps a new disease will be let loose on the human race, causing suffering on a large scale. Perhaps a grotesque and irreversible genetic reality will reap violence. Like Frankenstein, our geneticists may inadvertently create an unstoppable monster. We will then be sorry that we had altered the nature we inherited in our DNA. We must stop our scientists before they lead us past the point of no return, or so it seems.

Together these three beliefs associated with the gene myth look like something sensitive Christians should take on as a concern. The gene myth includes a version of the fall into sin. According to the gene myth, human *hubris* or pride expressed by our scientists will lead us to violate something in nature; and nature will retaliate violently with an uncontrollable disease or something similarly damaging. The ancient myth of Prometheus, who was punished by the god Zeus for stealing fire from the sun, has appeared again in the modern world in the form of the Frankenstein myth. In our modern era, the Frankenstein scientist steals secrets from nature; and then nature takes its revenge by letting loose uncontrollable and violent forces. The genetic version of the Frankenstein myth can be seen in the once popular movie, *Jurassic Park*.

When we formulate our faith response to the frontier of genetic research, how should we treat the gene myth? Can we distinguish between solid science and its mythical overlay? Can we take the science more seriously than the myth? How should we address the fear that the myth can create, even while we approach genetic science with caution? On what basis can we criticize the myth if it seems to be leading us astray?

## Does the science of genetics deny freedom of the will?

The gene myth results from the interactions of science and culture. Right or wrong, many Americans rely upon the gene myth because it is the dominant lens through which we interpret genetics science; and the science in turn seems to feed the validity of the myth. To get at the interaction between science and culture, three different approaches to genetics need to be distinguished and understood.

The first genetic science is *molecular biology*. Molecular biology pursues the chemical analysis of DNA; identifies the nucleotides which make up our chromosomal strands; locates protein producing genes and their promoters; and tracks gene expression. Molecular biologists look for specific genes or combinations of genes that are responsible for heritable traits or dispose us toward certain diseases. Molecular biologists recognize that genes are influential on our bodies, to be sure; but they see our genes more as a predisposition with a range of possible phenotypic outcomes rather than a strict determinism.

The second science is *behavioral genetics*. Behavioral geneticists examine statistical data about behavior which correlate to heritable traits. Among the traits they study are schizophrenia, depression, anxiety, and alcoholism. Behavioral geneticists often study identical twins, fraternal twins, and full siblings, half siblings, and step-siblings to sift out behavioral patterns that appear to be determined more by the genetic relationship than through social relationships. Some results of such studies are striking in what they reveal about the apparent power of the genes to influence our behavior. Yet, studies also reveal dramatic



differences in behavior between persons with identical or similar genomes. This implies that our behavior cannot be reduced to DNA alone. Recently, molecular and behavioral geneticists are collaborating to locate genetic predispositions to maladies such as bipolar and other affective disorders. Learning more about the genes identified with well-defined disorders, such as bipolar disease, may help to elucidate the pathways enabling more effective treatment and improved quality of life.

The third approach to genetics is *sociobiology*. Sociobiology is an interdisciplinary science that attempts to explain social behavior in all species by considering the evolutionary advantages the behaviors may have. It investigates social behaviors like violence or kinship in nonhuman species and uses them to illuminate human social behavior. Sociobiologists contend that genes play a central role in human behavior and that variation in traits such as aggressiveness can be explained by variation in peoples' biology as well as social environment. Sociobiology is based on the idea that some behaviors (both social and individual) evolved over time. The discipline explains behavior as a product of natural selection and as an effort to preserve one's genes in the population. Inherent in sociobiological reasoning is the idea that certain genes or gene combinations that influence particular behavioral traits can be passed from generation to generation.

Critics of sociobiology often complain that its reliance on genetic determinism, especially of human behavior, provides tacit approval of the status quo. If male aggression is genetically fixed and reproductively advantageous, then male aggression seems to be a biological reality (and, perhaps, a biological good) about which we have little control. This seems to be both politically dangerous and scientifically implausible. Genetic determinism, in fact, does not establish our individual personhood or identity. Who we are as an individual self does incorporate the influences of gene expression, but we are also greatly influenced by our environment. Our family, childhood experiences, social location, our baptism, and the significant choices we make contribute to identifying us as who we are. We are our stories. We are our biographies. And each of our biographies includes all our relationships, including our relationship with God. The appearance of our self-consciousness and personal identity emerges well beyond the strict domain of gene influence.

Genetic determinism in the sense of genetic predisposition is real. But genetic predisposition does not exhaustively predetermine. Our genome provides us with a wide range of possibilities within a frame of both opportunity and limitation. This genetic frame does not in any way undercut or make delusory our daily experience of free will. Our freely made choices are also real. Who makes these choices? Our DNA? The *self* makes choices. The self makes decisions and determines what actions we will take. Our genomes provide the enabling substrate upon which our personal self is constructed; and this self emerges as a distinct reality above and beyond our physical substrate. What we experience as human freedom is actually a three part determinism: our free action is determined (1) by our genome (our nature), (2) by the environment in which we live and grow (our nurture), and (3) by the decisions we make and the actions we take that determine key events in our life story. Genetic determinism is not incompatible with self-determination—that is, with what we know as every day free and responsible activity.

## Can genetics explain sin? Grace?

Consider again the above quoted passage from the Augsburg Confession: "Since the fall of Adam, all human beings who are propagated according to nature are born with sin, that is, without fear of God, without trust in God, and with concupiscence." That is, humans are born with the passionate desire to compete, steal, plunder, own, exert power over others, and so on. We have no freedom here; we must accept the birth we have been given. Humans are simply born with the innate drive to survive. Does this explain scientifically what Christians have meant by the term *original sin*?

Long before the age of genetics, theologians distinguished between *original sin* and *inherited sin*. As genetic sciences advance, we might gain a scientific explanation for "inherited sin" as the result of what some thinkers are calling the "selfish gene," namely, a biological explanation for the propensity for selfishness and violence that each generation

of human beings exhibits. It might explain human phenomena such as xenophobia, racism, nationalism, and jingoism. It could not explain every form of discrimination, however. Sexism, for example, could not be the result of a “selfish gene” because the genomes in men need women to win in the genetic struggle for existence.

While the search for one gene to explain all human evil seems misguided, the genetic sciences may give us insights into human evil. Current developments in molecular biology and behavioral genetics could make the science of inherited sin look quite different. Rather than rely on the idea from sociobiology that all DNA seeks to replicate itself, molecular biologists and behavioral geneticists are looking for specific gene configurations that connect with specific forms of behavior. Advances here may allow us to know that one individual might be more disposed toward violent behavior than his or her neighbor, due to the specific genes they possess. Some experiments have already shown that within extended families genetic markers can identify those individuals more prone to antisocial behavior or crime than those whose lives are more conventional and responsible. In this case, the theological concept of inherited sin would be illuminated by genetic science. Some of us inherit a greater propensity for concupiscence (evil desires, evil lusts) than others.

When Christian theology looks for insight from the genetic sciences, it may find illumination for the concept of inherited sin, but not for original sin. When theologians use the concept of original sin they refer to the situation of estranged existence that characterizes all life in God’s creation. We speak of the world as “fallen.” Regardless of what is in a person’s particular genome, all of us are members of a single human race that is both estranged from God and graced by God. Our behavior, whether criminal or virtuous, does not affect original sin. St. Paul writes in 1 Corinthians 15:22: “for as all die in Adam, so all will be made alive in Christ.” Paul’s reference to death in Adam refers to what theologians identify as original sin and being made alive in Christ refers to God’s grace whereby sinners are forgiven and the dead are raised. Nothing in the genetic sciences seems capable of illuminating our understanding of the dialectic between sin and grace.

Can our genes become a means of God’s grace? Yes, a Lutheran would say. This is because we believe God can use the physical realm for gracious action. In the Incarnation, God used the physical body of Jesus as a means of redemption. The physical element of water in Baptism, along with bread and wine in the Eucharist, are means of divine grace. So, it should not surprise us to find occasions in which divine action takes place at the genetic level. This is not to say that our genomes are by definition sacred. This is not to say we should embrace the gene myth and contend that our essence or our identity is to be found in our genomes. Rather, we ought to think of genes as simply one more aspect of the physical world, even if a wondrously complex aspect. Like anything physical, our genotype is part of God’s creation and potentially a means through which God can show love and favor.

## Invitation to conversation, prayer, and action



### QUESTIONS FOR DISCUSSION

- What principles for action seem to emerge from the new genetic sciences?
- Is the knowledge that we gain from the genetic sciences relevant to being faithful people? Does it help us understand Christian belief or how to be better disciples of Christ?
- Should Christians celebrate the advance of the genetic sciences and their potential for improving human health and wellbeing? Do we need to be more knowledgeable about genetics?
- How should we think about human identity and human freedom in light of this new science? Is our identity defined by our genes?
- If we commit a moral wrong or break the law, can we claim innocence on the grounds that “my genes made me do it”? Does genetic determinism governed by our DNA absolve us of personal moral responsibility?

- Should we respect the role gene expression plays in making our bodies what they are? How so?

## *Closing prayers*

### INVITATION TO INTERCESSORY PRAYER

Pray for biologists and theologians, mental health providers, and those suffering with mental illness.

### PRAYING WITH THE TRADITION

O Lord, you are my Lord and my God, yet I have never seen you. You have created and redeemed me, and have conferred on me all my good, yet I know you not. I was created in order that I might know you, but I have not yet attained the goal of my creation. I confess, O Lord, and give you thanks, that you have created me in your image so that I might be mindful of you and contemplate you and love you. I seem not to understand in order that I may believe, rather I believe in order that I may understand. Amen.

(Prayer of Anselm, who lived from 1033 to 1109)



# Genetics and Social Location: How do things look from here?

## Gathering

### HYMN

# 83 “Jesu, Jesu, Fill Us with Your Love,” or #230 “I, the Lord of Sea and Sky,” in *This Far By Faith: An African American Resource for Worship*. (For additional suggestions see page 119.)

### PRAYER

Holy Wisdom, giver of all life and source of all creating, we give you thanks that your Spirit moves throughout the world, transforming us and calling us to you. In faith and trust we bring to you our uncertainties, our fears, our questions, and our hopes. Free us in Christ for service to our neighbor as we dwell in your Word and listen for your Spirit. Guide us, we pray, in Christ’s name. Amen.



### HEARING THE WORD

Galatians 3:23-29

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

In this session, you are asked to reflect upon the significance of social location for assessing the ethical dimensions of genetic research and treatments. The focus will be upon communities of color and women of color. You will be asked to reflect upon your own social location and how it has shaped your ethical worldview.



### Real life stories

Genetic research and technologies have many and varied potential implications for human beings and communities. Consider these contrasting examples:

1. Gustavo is a 20-year-old Mexican American who lives in San Diego. He and his friends were recently approached by police on a street corner and asked for a genetic sample from their cheeks via a swab. The police are looking for a rapist via a genetic match. Gustavo and his friends are all legal residents of the U.S., but they still felt intimidated by the police and submitted to the spontaneous request. As it turns out, all of them were confirmed to be innocent. However, their genetic records are now a permanent part of the San Diego police department database.

2. Sandra is an African American woman living in Minneapolis whose mother died of breast cancer. She knows that as a Black woman, she has a higher mortality risk from breast cancer than a white woman. She wonders if she has a genetic predisposition for breast cancer. However, she is afraid to have a genetic test because she is uninsured and it would be costly. In addition, if she has the test and finds out she does have the gene, BRCA 1, she worries if she will be able to get a job with benefits. It may be that the company’s insurance carrier will not cover her if she gets breast cancer—that they will consider



Paul is opposed to circumcision being the sign of God’s covenant with us in Christ because, as a mark in the flesh, it causes pride among those social groups who can receive it and estrangement among those social groups who can’t.

What pairs of social groups today might you add, who, despite Paul’s best efforts, are estranged from each other within the Christian church?

it either as a pre-existing condition or that they will simply not write a policy that covers breast cancer because they see her as a high risk.

3. Sam ranches on land that has been in the family since the 1850s, and Sam is committed to continuing to ranch. Sam has gone to Dr. Olsen who provides medical care for the entire family (spouse and sons). Lately, Sam has had uncontrolled shaking of his arms. He has fallen several times. After some tests, Dr. Olsen suspects Parkinson's Disease. Dr. Olsen recommends that Sam go to the city to have more tests. Sam and his family do not have health insurance and they have nothing to sell to pay for medical care. Sam does not want to sell the ranch. He wants to keep it in the family so his family and grandsons have a place to live and work. Therefore, Sam asks his doctor to keep this between them.<sup>1</sup>

4. Maribel is a 28-year-old Puerto Rican woman living in Chicago who is newly pregnant and who receives some public benefits. She is excited to be pregnant. Maribel lives on the third floor of a walk-up apartment building. Her doctor suggested that she have early genetic testing done to ensure the health of the fetus. An amniocentesis showed that the fetus has a genetic abnormality, but the severity of any disabilities is not known and cannot be known until after birth. Her doctor asks her to consider what she will do if she decides to continue with the pregnancy and, upon birth, it is discovered that the child will not be able to walk. How will she be able to transport the child if a wheelchair cannot get up to her apartment? Maribel feels frightened, confused, and conflicted. She does not know her doctor well, but thinks he may be trying to steer her in the direction of having an abortion. She is not sure she trusts him.

## The importance of context for considering genetics

Genetic research, therapy, and technology never take place in a vacuum; instead, they are always situated within specific contexts. In other words, when thinking about when or if to make use of genetics in medical care and research, we need to attend not only to scientific facts, but also to social ones. In a world where we do not love all neighbors equally, and where social relationships are permeated by racial-ethnic, socio-economic, and global health and healthcare disparities, attentive consideration of particular people, places, and contexts is integral to the process of moral deliberation.

Many multilayered questions and complexities surround genetic research and its applications, especially as they relate to communities of color and/or those of low-salaried socio-economic classes. Indeed, Christians need to reflect not only on the general question, "Will this genetic research or technology benefit humanity?" but also on specific and contextual ones such as, "Which lives will benefit? Are particular people/communities at risk of being left out or mistreated?" Racial, ethnic, and socio-economic class realities (both in the United States and around the world) all interplay within the field of genetics in complex and varied ways. In some potential uses, genetics may be a tool for greater health and equality in society. In others, it may only reinforce prevalent stereotypes, racial bias, and socio-economic inequalities.

As Christians, then, we have to ask some hard questions of ourselves and others: In what ways does one's social location shape how one perceives and values genetics and genetic research? Who stands most likely to gain from the benefits of genetic research? Given the health and healthcare disparities prevalent in communities of color, is genetics more likely to reduce or intensify those disparities? In what ways might genetic technologies open the doors to greater racial, gender, and class discrimination and stigmatization? How do we protect the rights of individuals and population groups who have experienced abuse by genetic research in the past? These questions related to social location may make some uncomfortable, but they are nonetheless central to our collective moral reflection. In fact, the reality that they are thorny and put us ill at ease is probably a good sign that they are all the more important to address!

Before delving into these questions, however, it may be helpful to come to some common understandings about the terms being used.



## Social location

*Social Location* refers to the fact that human beings are “located” in a myriad of social relationships and identities that shape who they understand themselves to be, their values and aspirations, and their perceptions of others and the world they inhabit. Central aspects of one’s social location include: race/ethnicity; socio-economic class; rural or urban background; gender; educational background; sexual orientation; religious affiliation; mental/physical abilities; age; and nation or culture of origin. These combinations of identity, group memberships, and social relations affect a person’s or a community’s experiences, attitudes, assumptions, and beliefs (a.k.a. worldview).

For example, living in a large metropolitan area such as New York City, Chicago, or Houston is very different than living in a small rural town in Nebraska, South Carolina, or North Dakota. However, those who are poor in either the metropolitan or rural context are more likely to lack the economic and political means for gaining the full benefits of genetics and genetic research. For example, in one of the stories above, Sam has no health insurance and does not want to sell the ranch to pay for potential medical bills because he wants to give his grandchildren a place to live and work. So, taking advantage of medical resources in the city and potential genetic therapies that may become available would create a hardship on his family and extinguish his dream of keeping the ranch in his family. Like some ranchers and small farmers, Sam has to weigh the benefits of seeking state-of-the-art genetic research and future therapies versus providing for his family. Poor and disenfranchised communities in either rural or urban areas, especially those of color, have been most at risk of being negatively affected by medical research, and most often lack access to new therapies, as will be explored below.

The point is, then, that the particular lens through which a person or community tends to look out at the world, is profoundly affected by their social location. That said, it is important to note that no person or community is simply a “victim” or “powerless” in terms of their social location or can be neatly labeled “oppressor” or “powerful.” For example, a white professor in a classroom of undergraduates possesses significant authority and power *vis-à-vis* her students. However, that same professor does not enjoy the same innate privilege and power walking home alone at 9 p.m. on a street that is not especially well lit. Simply put, it is part of human life that in some contexts every human being experiences themselves in a position of power relative to others; while in different contexts, he or she experiences themselves as less powerful in relation to others.

Second, no person is “chained” to the social location into which they were born. While some of these identifications associated with social location are given, e.g., genetic make-up and place of birth, other aspects are open to at least some adaptation—they can be chosen, changed, or expanded upon, e.g., religious affiliation, linguistic background, and vocational identity. However, race, gender, and socio-economic class identities are not easy to change for most of us. And most of us know that we are immediately identified and categorized by these traits whenever we walk down the street, apply for school, interview for a job, or walk into a bank office. Whether we like it or not, people often make assumptions (for good or for ill) about others based on their skin color or clothing.

Finally, social location matters regardless of a person’s personal beliefs. For example, not everyone who is white believes black people are less intelligent and less hard working than white people. In fact, it is very possible that very few white people consciously subscribe to such beliefs. Yet, an individual’s beliefs actually have little to do with her or his access to privilege, power, and important institutions that govern our common life.<sup>2</sup> Independent of one’s actual conscious beliefs, it is social location that often grants or denies access to privilege and power. Furthermore, even if no one consciously holds stereotypical or prejudicial beliefs, it is still possible for institutions, organizations, and common practices to discriminate (even if unintentionally) against particular groups or populations.

## Communities of color

With respect to social location, the use of racial/ethnic categories is sometimes seen as helpful and sometimes as not helpful. This is a difficult subject to discuss because, as

*Social Location* refers to the idea that human beings are “located” in many social relationships and identities that shape their self-understanding, values and aspirations, and their perceptions of others and the world. Examples of these relationships include race/ethnicity; socio-economic class; gender; religious affiliation; mental/physical abilities; and age.

Christians, we tend to strive to look beyond a person's racial/ethnic background, their gender, or their economic status and see them simply as a child of God. Unfortunately, we also tend to put all people who appear to have certain traits into one group without recognizing the uniqueness of the individual's or group's experience. For example, although they share racial background, one cannot put all African Americans on the North American continent together with all African Americans living in the Caribbean. Similarly, one cannot put Latino/Latina and Mexican American communities into one population group. While there may be commonality of language, there are different social experiences. The term, *communities of color*, refers to how historically disadvantaged racial/ethnic groups have named themselves.

In genetics, racial/ethnic categories are imprecise and difficult to define. Geneticists and genetic researchers support two views on the use of such categories. On the one hand, there are those who suggest that the use of racial/ethnic categories is not helpful in genetic research. They believe this type of thinking leads to misinformation about the human genome and can lead to further discrimination and stigmatization. On the other hand, there are those who suggest that the use of racial/ethnic categories is helpful in reducing health disparities. BiDil, a combination of two drugs, developed for African Americans suffering from heart disease, is an example of such research and has been met with mixed appraisals.<sup>3</sup>

It is important to understand that race and ethnicity are not biological realities. They are social realities. Genetic differences do not neatly line up with the racial categories we have constructed. An African American and a white person may share much of the same genetic makeup, and an African person from Ethiopia may have a different genetic makeup than an African American from the U.S. or the Bahamas.<sup>4</sup> It is imperative that we neither ignore possible genetic clues for the diagnosis and treatment of disease, nor overuse genetics to explain the causes of illness and behavior while missing other key environmental and social factors such as stress, racism, poverty, exposure to environmental toxins, poor nutrition, etc.

In the ELCA's social statement, *Freed in Christ: Race, Ethnicity, and Culture*, racism was identified as a prominent environmental factor that shapes one's perspective on and experience of cultural developments. Let's consider, from recent U.S. and Caribbean history, how race/ethnicity and racism shape the experience of communities of color and impact their perspective on the use of genetic technologies.

## Reasons for caution and mistrust—lessons from history

One of the incontestable facts of life in the United States and the Caribbean is that we live in a multiracial and multiethnic society. Increasingly, within this diverse society, communities of color experience the health care system in ways that are different from how most white Caucasians experience it, ways that shape their understanding and perceptions of rapidly developing genetic technologies. These experiences, each different, yet grounded in a common experience of abuse and racial/ethnic discrimination, create caution or mistrust of the goals and purposes of anything related to genetics. It is true that, for many in communities of color, genetic research does not figure prominently. However, they do experience the healthcare system, a field in which genetics is beginning to play a dominant role. This history lends vital context for understanding the roots of mistrust and caution among certain communities of color about genetics.

### African American experiences

African American communities have a “both/and” perspective on the use of genetic technologies. Some believe that the federal government actively conducts unethical genetic research (especially on the prison population), and are less optimistic about genetic research. Yet, other African Americans are optimistic about the good of genetic research.<sup>5</sup> Still, among African Americans, there are concerns about discrimination based on genetic information. These perspectives may have their roots in two major events: the United States Public Health Service (USPHS) Study of Untreated Syphilis in Negro Males in Macon County, Alabama and the Sickle Cell program initiated in the 1970s.

The USPHS Study has powerfully shaped how many people in the African American community view healthcare givers and researchers. From 1932 to 1972, this study used 399 poor African American males who had syphilis and 201 African American males free of the disease to observe the effects of untreated syphilis on the body. The participants were never informed that they had syphilis, resulting in a complete lack of informed consent. Rather, they were told they had “bad blood,” and were consistently denied effective treatment, i.e., penicillin, when it became available. Indeed, penicillin became the standard treatment for syphilis as early as the mid-1940s. The study only ended in 1972 because of a leak to the press and public outrage. Originally, the study was to last until “the last participant died.” Keep in mind that this study went on for 40 years! Not surprisingly, the long shadow of the USPHS study contributes to the caution and mistrust felt by many African Americans with respect to the federal government and the delivery of medicine and healthcare to African American people.<sup>6</sup>

Toward the end of the syphilis study, the federal government instituted a sickle cell screening program targeting the African American community. Prompted by the death of four African American Army recruits between March 1968 and February 1969, the President of the United States signed into law the National Sickle Cell Anemia Control Act. This bill authorized federal funds for screening, education, and research.<sup>7</sup>

There was some skepticism at the news that a health program had been instituted and funded by the federal government to address an unknown genetic disorder in African Americans. Some of this skepticism may be attributed to the way government physicians mistreated poor African American males in the United States Public Health Study of Untreated Syphilis in Negro Males. Some of the skepticism may also have come from the claim of a genetic disorder specific to African Americans, and some may be attributed to misinformation and misunderstanding about sickle cell disease (SCD) and sickle cell trait. For example, it was said that SCD affected only African Americans. This was far from the truth. SCD also affected persons from the Mediterranean and Africans on the continent of Africa. The proliferation of screening programs (today in all 50 states), though, was initiated to screen school children and those applying for marriage licenses for the sickle cell trait. Some members of the African American community perceived this as a way to restrain the reproduction of people who society considered to be unfit (sometimes called “negative eugenics”).<sup>8</sup>

For African Americans, then, concerns about racial discrimination and stigmatization were not completely unfounded. Initially, the U.S. Air Force denied African American recruits the opportunity to fly airplanes if they tested positively for the sickle cell trait. At the turn of the twenty-first century, the Armed Forces of the United States had a variety of policies related to sickle cell. Some branches tested (the Marines, Air Force, and the Navy) while the Army was reviewing its policy.

On the other hand, genetic research on sickle cells holds great promise for those affected by the disease. Consider this example: Keone Penn, a young African American male, suffered from sickle cell disease. His red blood cells would develop into a sickle rather than the normally round red blood cells. Keone had been hospitalized with chronic pain and a stroke. Since bone marrow could not be obtained from either his family or other donors, doctors tried an adult stem cell transplant from an unrelated umbilical cord. After this history-making surgery, Keone was declared cured of sickle cell disease.<sup>9</sup> Nevertheless, the controversy over SCD and sickle cell trait points to various reasons why African Americans may have ambiguous feelings toward genetic technologies.

### **The experience of women of color**

The issue of environmental factors may become clearer in the experiences of Latina women. These factors are clearly present in the area of reproductive choice and family planning. What is astounding is the striking similarity of the experiences of women of color with respect to their ability to control their own bodies, and the role of government, science, and medical practitioners in those experiences. The issues of sterilization and informed consent emerge out of the experiences of women of color related to genetics.

The use of sterilization has a long tradition on the North American continent and in the Caribbean. Among Latina women, this practice has been going on since WWI. Called “La Operacion,” this program, by 1965, had sterilized more than 20,000 Latina women in Puerto Rico. Aided by government funding, the medical establishment, and the local government in Puerto Rico, poor women became targets of those who wanted to control population growth. It was thought that controlling population through sterilization would help stem the economic crisis in Puerto Rico. Clearly some Latina women experienced sterilization as coercive; that is, doctors were able to legitimize this practice without the informed consent of the women. In other cases, Latina women sought the practice as a form of birth control because they had no other resources. Race and class influenced their reproductive choices.<sup>10</sup>

Many of the same dynamics involved in the mass sterilization of Latina women in Puerto Rico are evident among African American women on the North American continent. Sterilization served as a method of reducing the population, as a form of birth control, and as a way of controlling “promiscuous” behavior. This practice revived the eugenics argument because sterilization is a form of negative eugenics; that is, a method for prohibiting poor “undesirable” women from procreating. States were permitted to enact legislation that allowed sterilization of poor African American women.<sup>11</sup> Doctors and social workers could determine whether a poor African American woman needed sterilization. Moreover, involuntary sterilization was common throughout the South. A prominent woman of the Civil Rights Movement, Fannie Lou Hamer, suffered what came to be known as “Mississippi appendectomies,” that is, sterilization without their informed consent.<sup>12</sup> While there was involuntary sterilization, some African American women actively sought sterilization; however, they did so only because they had no access to other methods of family planning.

Sadly, such problematic proposals are not merely a thing of the past. In September 2008, a Louisiana State Legislator, John Labruzzo, was among those who floated the idea of paying poor women \$1,000 to have tubal ligation (“tube tying”) in an effort to combat the cycle of poverty and dependence on government aid, what he termed “generational welfare.” This proposal is ethically problematic because, instead of looking at the roots of cyclical poverty, it simply seeks to control reproduction of certain socio-economic classes—and by extension of certain racial-ethnic communities.<sup>13</sup> In short, Latina and African American women may have more difficulty than others trusting healthcare providers around reproductive issues, due to socio-economic inequalities and/or racial-ethnic dynamics.

It is important to understand that poor women, especially those of color, have often felt caught in a system of healthcare where they had limited access to both adequate reproductive care and other healthcare resources when they needed them. In short, the larger story of medical research and development is one not only of progress, but also of inequality. Consider artificial reproductive technologies (ARTs) such as in vitro fertilization. It is largely the well-insured and generally wealthy who can afford such technology. It is not covered by all insurance plans and largely uncovered by public insurance programs such as Medicaid.

### Global impact of medical research

Finally, it is important to note that questionable research and medical practices are not simply a lamentable part of North American and Caribbean history. There are reasons for concern even today. For example, the first AIDS drugs were tested on African peoples; however, African peoples have largely been excluded from benefiting from the approved drugs that resulted from these early trials. This reality is changing somewhat, but there are still huge drug and healthcare access disparities between the United States and Africa, or between the First World and the Two-Thirds World in general. Or, consider the fact that millions die every year of TB and Malaria, both preventable and treatable diseases that do not ravage the West, but which are endemic to much of Africa and Asia.

Simply put, most of the world does not benefit significantly from current medical

cures, treatments, and therapies that we enjoy in the United States. It is possible that genetic therapies will only deepen this health and wellbeing divide unless there is sufficient public demand for fair distribution across national borders.<sup>14</sup> We Christians in the United States and the Caribbean need to reflect seriously on these facts and contemplate what is required in order to express authentic love of neighbor, and to seek justice among different people and nations.

## Conclusion

The relationship between genetics and social location is a long one on the North American continent and the Caribbean. Environmental factors such as race, socio-economic class, politics, and gender shape how various communities of color view the contributions or non-contributions, the promise or threat of genetic technologies.

The ELCA's social statement, *Caring for Health: Our Shared Endeavor* (2003), suggests that healthcare is a "shared endeavor." The use of technology and research is both embraced and viewed with caution. The lessons of abuse experienced by communities of color call us to listen to and work with these communities in their pursuit of "being well."

## Invitation to conversation, prayer, and action



### QUESTIONS FOR DISCUSSION

- How does your own social location affect how you think about and view the prospects of genetic research and new technologies?
- Have you, or loved ones, ever had difficulty accessing United States healthcare? What obstacles did you/they encounter?
- Have you ever felt judged or stereotyped by a healthcare provider, members of your community, or genetic counselor?
- What theological and ethical insights have emerged for you upon reflecting on how racial/ethnic and socio-economic inequalities affect communities of color and women with respect to their perspective on and experience of genetics?
- In what ways does Galatians 3:27-28 impact your understanding of human beings? Read Jeremiah 8:17-22 and discuss the implications of that text for your understanding of social location. Who are the people that are underserved in your community? What ethical/theological principles emerge for you relative to genetics and social location? In what ways does Luther's explanation to the First Article of the Apostles' Creed apply to the situations identified in this session?
- Action question: In what ways can you and your congregation express love of underserved people in your community?

## Closing prayers

### INVITATION TO INTERCESSORY PRAYER

Pray for sociologists and community organizers, the marginalized of society and those who advocate on their behalf.

### PRAYING WITH THE TRADITION

We thank thee, O God, for the spiritual nature of [human beings]. We are in nature, but we live above nature. Help us never to let anybody or any condition pull us so low as to cause us to hate. Give us strength to love our enemies and to do good to those who spitefully use us and persecute us.... Keep us, we pray, in perfect peace. Help us to walk together, pray together, sing together, and live together, until that day when all God's children, black, white, red, yellow, will rejoice in one common band of humanity in the kingdom of our Lord and God. Amen.

(Prayer of Martin Luther King Jr., who lived from 1929 to 1968)



## Additional resources

### Web sites and videos on US and Global Health and Healthcare:

“*Lifeline*” A *60 Minutes* segment on the U.S. uninsured; and “Remote Areal Medical (RAN), a non-profit charity organization which operates temporary medical clinics across the United States and throughout the world (aired July 14, 2008); online: [www.cbsnews.com/video/watch/?id=4256735n%3fsource=search\\_video](http://www.cbsnews.com/video/watch/?id=4256735n%3fsource=search_video)

“Sick Around the World” - A PBS *Frontline* Special that aired April 2008. It compares U.S. healthcare costs, quality, and access to that in England, Germany, Japan, Taiwan, and Switzerland and suggests what the U.S. might learn from these models. You may watch the program online: <http://www.pbs.org/wgbh/pages/frontline/sickaroundtheworld/>

The Commonwealth Fund: [www.commonwealthfund.org](http://www.commonwealthfund.org) See for example:

*Racial and Ethnic Disparities in U.S. Health Care: A Chartbook* (2008)  
[www.commonwealthfund.org/publications/publications\\_show.htm?doc\\_id=672908](http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=672908)

“Why Not the Best? Results from the National Scorecard on U.S. Health System Performance, 2008” (2008) [www.commonwealthfund.org/publications/publications\\_show.htm?doc\\_id=692682](http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=692682)

Physicians for a National Healthcare Program: [www.pnhp.org/](http://www.pnhp.org/)

### Global Health & Healthcare & Social Justice:

“Dr. Farmer’s Remedy,” A *60 Minutes* segment on the life and work Paul Farmer which aired May 4, 2008); online: [www.cbsnews.com/video/watch/?id=4069409n%3fsource=search\\_video](http://www.cbsnews.com/video/watch/?id=4069409n%3fsource=search_video)

A Frontline Program on Global Health & Healthcare:  
[www.pbs.org/wgbh/pages/frontline/sickaroundtheworld/](http://www.pbs.org/wgbh/pages/frontline/sickaroundtheworld/)

A PBS Series -- *RX for Survival: A Global Health Challenge*:  
[www.pbs.org/wgbh/rxforsurvival/](http://www.pbs.org/wgbh/rxforsurvival/)

Global Health Facts & News: [www.globalhealthfacts.org/](http://www.globalhealthfacts.org/)

Partners in Health: [www.pih.org](http://www.pih.org) Also see: *Farmer’s Pathologies of Power & Mountains*

*Beyond Mountains* by Tracy Kidder

Doctors without Borders: [www.doctorswithoutborders.org/](http://www.doctorswithoutborders.org/)

## Endnotes

1 This story is an adaptation of “It’s a Matter of Priorities,” a case study prepared by the National Rural Bioethics Project, The University of Montana – Missoula.

2 According to the U.S. Census Bureau, the U.S. population equals 303 million inhabitants. Of this total number, non-Hispanic whites comprise 67% of the overall population. However, only 10.8% of non-Hispanic whites are uninsured and only 8.2% are impoverished. For their part, African Americans constitute 12% of the general population and Latino/Latina Americans make up 14.5%; yet both communities suffer disproportionately from the twin hardships of being uninsured and/or living in poverty. 24% of African Americans are poor and 34% of Latinos/Latinas are uninsured. Finally, consider the make up of our national elected leadership. In the 110<sup>th</sup> U.S. House of Representatives (435 members total), 74 members identify as women; 42 as African American; 24 as Hispanic American; 1 as Native American; and 6 as Asian American. And in the U.S. Senate: (100 members total): 16 are women (35 women have served in the Senate’s history); 1 is African American (5 have served in the Senate’s history); 2 are Asian American (5 in the Senate’s history); 3 as Hispanic American (6 in the Senate’s history); and 0 are Native American (a total of 3 in the Senate’s history). See [www.house.gov/daily/hpg.htm](http://www.house.gov/daily/hpg.htm) and [www.senate.gov/pagelayout/reference/three\\_column\\_table/Senators.htm](http://www.senate.gov/pagelayout/reference/three_column_table/Senators.htm).

3 Joanna Mountain and Neil Risch, “Assessing genetic contributions to phenotypic differences among ‘racial’ and ‘ethnic’ groups,” and S.O.Y. Keita, R.A. Kittles, et al. al., “Conceptualizing human variation,” *Nature Genetics* November 2004, Vol. 36, No. 11, s54 and s17 respectively.

4 See the engaging research led by Henry Louis Gates Jr., featured on PBS, that traces the genetic ancestry of African Americans. Available at: [www.pbs.org/wnet/aalives/profiles/index.html](http://www.pbs.org/wnet/aalives/profiles/index.html).

5 Paul Achter, Roxanne Parrott, and Kami Selk, “African Americans’ Opinions about Human-Genetics Research,” *Politics and the Life Sciences* June 21, 2005: Vol. 23, No. 1.

6 See James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment*. New York: The Free Press,



1993); Emilie Townes, *Breaking the Fine Rain of Death*.

7 "Statement on Signing the National Sickle Cell Anemia Control Act," John T. Woolley and Gerhard Peters, *The American Presidency Project* [online]. Santa Barbara, CA: University of California (hosted), Gerhard Peters (database). Available from World Wide Web: [www.presidency.ucsb.edu/ws/?pid=3413](http://www.presidency.ucsb.edu/ws/?pid=3413).

8 James E. Bowman, "Genetic Screening: Toward a New Eugenics?" in *"It Just Ain't Fair: The Ethics of Health Care for African Americans*. Edited by Annette Dula and Sara Goering (Westport, Connecticut: Praeger, 1994, 165-178) and Troy Duster, *Backdoor to Eugenics*. With a Forward by Pierre Bourdieu. Second Edition. New York: Routledge, 2003.

9 This story is a redaction of the *60 Minutes II: Holy Grail* presentation on June 5, 2002. Available at [www.cbsnews.com/stories/2001/11/28/60II/printable319351.shtml](http://www.cbsnews.com/stories/2001/11/28/60II/printable319351.shtml). Accessed September 22, 2008.

10 Sara Hoerlein, "Female Sterilization in Puerto Rico." Available at [www.clem.mscd.edu/~princer/ant440b/paper\\_04.htm](http://www.clem.mscd.edu/~princer/ant440b/paper_04.htm). Accessed June 29, 2008.

11 Johanna Schoen, "Between Choice and Coercion: Women and the Politics of Sterilization in North Carolina, 1929-1975," *Journal of Women's History*, Vol. 13 No. 1 (Spring, 2001), 132-156.

12 Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* New York: Vintage Books, 1997, 90-91.

13 See the CNN interview, "Tubal ligations for the poor" online at: [www.cnn.com/video/#/video/politics/2008/09/25/tubal.ligations.for.poor.cnn](http://www.cnn.com/video/#/video/politics/2008/09/25/tubal.ligations.for.poor.cnn)

14 For documentation of these claims, see the statistics available at: [www.globalhealthfacts.org/](http://www.globalhealthfacts.org/) and also from the World Health Organization ([www.who.int/en/](http://www.who.int/en/)) and from the United Nations (<http://hdr.undp.org/en/reports/global/hdr2007-2008/>). Finally, for fuller analysis of these realities, see Lisa S. Cahill, *Theological Bioethics: Participation, Justice, & Change* (2005)



# Genetic Testing and Screening: What do we choose to know?

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

In a world of wonders, we ponder where we have come from and where we are going. We wonder at the gifts of life and love, O God of the Universe, and we wonder at grace that draws us up and out and forward. Our genetic foundations and our species history speak of how we arrived here, but the wonder of your future for us remains mystery; we thank you. Teach us to pray, to hope, and to labor for the kingdom. Amen.



### HEARING THE WORD

Psalm 139:1-18, 23-24

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

This session invites you to learn more about genetic testing and screening and to reflect about the personal challenges it presents. Three examples are provided from real life situations. The session is designed for you to select one contemporary illustration: cancer genetics, prenatal testing, or teen at risk. After reading about the situation, read the “Common Territory” under “About Genetic Testing and Screening” and then the discussion paragraph for that illustration. The subsequent section is organized in the same way, but reflects on the issues in relation to theological matters. The questions at the end of the session are organized in the same pattern in order to allow discussion and deliberation on the illustration you have chosen.



### Real life stories

#### 1. Testing for disposition to cancer?

Fred has just learned that he has advanced prostate cancer at age 38. His sister died of ovarian cancer at 32, in 1995. After their parents died in an accident when they were in their 30s (both parents had been in good health), Fred and his sister were raised by neighbors because there were no living grandparents, aunts or uncles. Fred’s daughters are 14 and 11 years of age. Someone asks whether there might be a genetic predisposition to cancer in his family.

They have heard of a test that can inform people about such risks. Fred and his wife Glenda meet with a genetic counselor to learn more about their options. They learn that the test might show “nothing unusual,” which would mean either that his family has no special risk factor or that it exists but is outside the range of current testing technology. The test might show something that is “different from usual” but of uncertain significance, possibly important or possibly only a normal variation. The test might reveal a “specific abnormal gene structure” that brings with it high risks for cancer of the prostate, breast, and ovary.



The psalmist says, “I come to the end—I am still with you” (Ps. 139:18). What comfort do you find in these words amid the pokes and proddings of our medical lives?

They also learn that Fred's results might have profound meaning to his daughters. If he is tested and the results are "different from usual" or show "specific abnormal gene structure," it might open a path to reveal whether one or both of them have inherited a high risk of cancer from him. The geneticist explains that testing is discouraged for people who have not yet become adults and established their own plans as to what information they want and what they would prefer to leave unexplored.

While there are federal and state anti-discrimination laws, being labeled as a high-risk person can be uncomfortable. What does Fred want to know, and when does he want to know it? What does Glenda think? Should someone be talking to the deceased sister's son and daughter? How does Fred feel about all this, now that his treatment is completed but he is being asked to worry about the risks his daughters may have inherited from him?

## 2. Screening a pregnancy?

Fran is 36 years old and has two school-age children at home. She and her husband Greg had not planned it, but a new pregnancy is under way. They are inclined to accept this as a joyful challenge.

Her obstetrician proposes, along with what she considers ordinary obstetric care, genetic screening designed to learn whether this pregnancy faces higher than usual risks for chromosome abnormalities (e.g., trisomy 21, which causes Down syndrome) and/or birth defects (e.g., spina bifida, which can be crippling and cause developmental delays). She explains that the screening cannot reveal whether these problems are actually present, but only whether the *chance* of their being present is high enough to suggest that definitive testing should be offered. The screening involves one more tube of blood along with the others being taken from a vein in Fran's arm. The definitive testing would involve an amniocentesis, insertion of the needle into her abdomen to remove some of the amniotic fluid, so that specific genetic tests can be performed.

Since Fran has no known risk factors, amniocentesis will be offered only if her screen came back "positive" (elevated risks). In such settings, amniocentesis results usually come back normal, meaning that the alarm was a "false positive" rather than signaling an actual problem with the pregnancy. The doctor also encourages ultrasound examinations to monitor growth and development, but warns that ultrasound may reveal structural abnormalities known to cause severe disability, or other abnormalities of uncertain significance. What do Fran and Greg want to know about their pregnancy? When do they want to know it? Until now they have felt optimistic about their own health and the apparent normalcy of this pregnancy.

## 3. Testing a teenager?

At age 14, Tommy is approaching six feet tall. He is an honor student, and well coordinated with considerable talent for sports. Everything is going his way as he starts high school and looks forward to playing basketball; the team has a long history of being scouted by the best colleges.

Coach Jensen is eager to maintain her award-winning team and has heard about Tommy from his middle school teachers. But when she meets him, an inner alarm sounds. She notices his long flexible fingers and a slight curve to his spine when he removes his shirt on his way to the locker room. Having heard that Tommy's mother, who was also tall and slender, died in childbirth of a heart attack, she calls his father and asks that Tommy be evaluated for possible Marfan syndrome before participating on the basketball team. He is both alarmed and angry at the suggestion that they might have overlooked some important health risk and that Tommy's future in sports (and sports scholarships) may be in question.

An orthopedist announces that Tommy has Marfan syndrome. A cardiologist says that the echocardiogram reveals nothing abnormal in Tommy's heart and aorta, but warns that at his age the changes, which include dilating of the aorta, might not yet have developed; he offers to start prescribing medication which may protect the aorta from developing problems. A consultation with a geneticist is offered, but Tommy and his father worry that

a confirmation might prevent his continuing in sports, and they feel adequately protected by the cardiologist's opinion and treatment plan. What should they do? What should Coach Jensen do? Tommy's mother may have died of a ruptured aortic aneurysm (common in pregnancies of women with Marfan syndrome); should someone be talking to her surviving siblings, nieces, and nephews? Tommy's cousin Jane is over 6 feet tall.

## About genetic testing and screening

### Common territory

All of us have complexities that are evident to everyone who takes a glance at us, others that only we know quietly in our hearts, and still others that are outside the view of all but God. These mysterious factors, some favorable and others not, are tied up in a great bundle that is the gift we are from God to the world.

Our genome radically determines the limits of our possibilities. My genes will never allow me to fly like an eagle, or dive like a whale; technology allows me to imitate these activities, but not to do them myself. If I am severely damaged by mutations or by poisons or by traumas, the limitations on my possibilities will be narrowed irrevocably. Some of the ways in which I am genetically endowed make me stronger than you, while others weaken me. Some will manifest disorder and disability from even before I am born, others during my childhood, and others only much later in life.

Since we have some 3 billion subunits of information in each cell, and most of these are not directly involved in visible phenotypic features, there are millions of ways in which one person may be genetically different from another person, without either of them being impaired. Eye color is an obvious example. Green eyes are not "normal" as compared to brown eyes; one color is not "better" than the other biologically. The millions of differences between any two individuals make it possible to use genetic analysis to identify an individual at least as well as finger prints ever did—better, really.

Every child born in the United States is subjected to newborn genetic screening to learn if one of several dozen biochemical abnormalities might be present. Many of the screens flag children who in fact are "normal" and a more definitive test shows this, removing the concern that a disorder might be present. The standard definition of what should be screened in newborns is that the condition should be subject to interventions that improve the outcome for the child. Such interventions may be dietary, medical, or therapeutic.

### Cancer genetics

The notion of genetic predisposition is crucially important. Everyone accustomed to climbing stairs knows that occasionally a foot is not quite lifted high enough and one trips. Usually one does not drop one's burdens or actually fall, but recovers quickly and continues climbing. Sometimes one drops or spills things, sometimes one falls, and sometimes one is seriously hurt in the process. Some people trip on the stairs more often than others, through clumsiness, blindness, carelessness, interference, etc. Some just do it more often because of being *predisposed*. Tripping on the stairs is somehow just more a part of who I am than who you are.

People who are genetically predisposed to develop cancer will have a higher risk for it than others, but this does not mean that they will certainly develop it, nor does it mean that those others will not develop it. If my risk is 20% while yours is 10%, I may yet be more fortunate than you in the long run or I may die in an accident or a war or from an evil choice and not live long enough to show my proneness to tumors.

Genetic risk factors associated with breast cancer also illustrate another subtle but important detail about hereditary predispositions: changes in most genes are inherited and transmitted to future generations regardless of gender, both males and females receiving them and passing them along. But some of these risk factors are very different in their phenotypic effects as a function of the gender of the person receiving them (due to the internal hormonal environment and the details of anatomy).

## Prenatal screening

Modern technology makes it possible to observe considerable anatomic detail in a fetus through the use of ultrasound, and to determine genetic characteristics by a sampling of amniotic fluid or by conducting small biopsies from the placenta (or even the fetus) which give us cells to grow in the laboratory. Some methods involve the measurement of chemicals that, when higher or lower in concentration, are correlated to abnormalities in the developing fetus. These latter measurements are called “screening” techniques because they do not (cannot) prove or exclude an abnormality. They merely draw our attention to elevated risk rather than an actual abnormality, so that we can focus on those pregnancies for which definitive testing can be offered. Not every pregnant woman wants either tests or screens to learn of abnormal processes underway in their pregnancy; they prefer to wait until the time of birth to learn these things. They cannot forever avoid the knowledge, but they can postpone it.

## Teen at risk

Marfan syndrome is caused by mutation in a gene responsible for formation of one of the components of the connective tissue—bones, ligaments, walls of blood vessels, scaffolding of the lens suspended inside the eye, etc. There are dozens of physical characteristics that are commonly found in Marfan syndrome, most of them things that are also seen in many people who do not have the syndrome. Features shared with other people include tall stature, long arms, loose joints, spinal curvature. Several features that are seldom seen in non-Marfan people carry more weight in making the diagnosis: enlargement of the root of the aorta, dislocation of the lens of the eye, and an abnormally generous amount of space for the spinal column inside the lower back. Coaches are concerned about Marfan syndrome because healthy, tall, slender teens can have catastrophic events with dissection of the aorta and drop dead on a basketball court. But clinical delineation of the syndrome is complex because of the considerable phenotypic overlap of people who have Marfan syndrome with people who just have some physical features that bring Marfan syndrome to mind.

## Reflections for consideration

### Common territory

Notions of determinism enter the discussion at all major turning points in personal and corporate life. Do I act selfishly because of the ways in which I am constructed genetically, or the ways in which I have been shaped behaviorally, or with a radical freedom that leaves me wholly responsible for my bad choices? Questions of this kind await us around every corner in a discussion of genetics and faith. And if the answer is that my genes make me do what I do, then I must decide whether I think that is the result of blind accidents through evolutionary time or of direct planning and enforcement by God. Lutherans typically opt for a middle way, in which the force of events within and around me is acknowledged, but I am still expected to accept all the implications of freedom, which opens me to opportunities for sinfulness while foreclosing the excuses of victimhood.

### Cancer genetics

Watching closely and helplessly as loved ones are felled by cancer in their 40s can condition a person to feel fated to suffer the same events. Family dynamics can further complicate the picture; if I have been out of communication with my sister for 20 years because of an old dispute, will I contact her to warn her about the cancer risk I have just learned is moving through our family? In such situations, where are faith and grace in my life?

If my overall attitudes toward life are optimistic and I am prone to take charge of problems to seek out their solutions, I may be more inclined to opt for surgical efforts to reduce those areas of the anatomy at risk (e.g., breasts, ovaries, colon), rather than to watch with imperfect monitoring methods. If I am more passive in my life style, I may not be so assertive about risk management. And these different personality types themselves



probably stem from complex multi-factorial traits: genes, upbringing, environment, the history of accidental and decisional events in one's past.

## Prenatal screening

We may enjoy poetic reflection on Psalm 139, which marvels at how we have been knit together in our mother's wombs, but we should not allow that to overshadow the combination of joy and hope along with dread that is experienced when a pregnancy is underway. Parents are charged with the responsibility of providing prenatal, neonatal and pediatric care that includes nutrition, protection, education, nurturing, etc. How individual parents meet the challenges of these many arenas varies depending on their own internal capacity, and their available resources (financial, psychological, etc.).

Most of us most of the time would lay down almost anything in order to save our children from suffering and death. But some of us some of the time are faced with information that may lead us to think that death is preferable to birth, and so to elect pregnancy termination after prenatal diagnosis. Some of us do not want that information because we are certain that we could never be induced to elect termination or because (perhaps subliminally) we do not want to face such a temptation. If we do not know about the problem until it is too late to make termination decisions, then we narrow the field of options. This either enhances our heroism in making selfless choices, or it betrays cowardice in avoiding situations in which we might not choose heroism.

It is important to remember that prenatal testing is not designed to set up abortions, though the outcome after an abnormal result may be the choice to terminate. In a much larger context, these tests allow some families to better prepare for a child with special needs by reading and by speaking with other similarly affected families. In a few diagnoses, there are even prenatal interventions to improve prognosis.

## Teen at risk

The competing and overlapping roles of fear, hope, guilt, ambition, denial, and confusion can make decision making complex and painful. No sane parent looks for ways to place his or her children at risk, but who can say that there is not a strong temptation to avoid confronting facts that frighten by raising painful memories or uncovering our worst worries after years of clinging to fondest hopes? Where is my hope located—in my own best efforts? In my genes? In a risen Christ whose presence may seem elusive while the genome looms as pervasive? Who will fault the widower Dad who begins to suspect that the killer of his beloved wife might be emerging in his beloved son? Where does he turn now? Do we glibly invite him to prayer, or do we try with little hope of success to enter the maelstrom with him?

## Invitation to conversation, prayer, and action



### A QUESTION COMMON TO EACH SITUATION

- When scientific advances allow me to know more about what health problems are more or less likely to develop in my life, to what extent do my decisions about how to employ them depend on curiosity, fear, or the sense that I must take responsibility to be well informed in order to then pursue upright choices?

### QUESTIONS FOCUSED ON EACH STORY

- Should I seek out knowledge of my cancer risks at the genetic level in order to make better-informed career plans? To decide about whether to have children? To advise close relatives of the risk that they also might face?
- Is delving into the genetics of a pregnancy underway a means of expressing a sense of partnership with God in the creative enterprise? Or is it an interference with God's manifest will in the existing conditions to which I should not raise my hand in objection?

- How much testing and seeking is enough? What level of risk should a parent take in decisions about pursuing a possible genetic problem in a teenage child when physicians called for consultation differ in their perspectives? What is appropriate when major life options may open or close on the basis of the answers obtained?

### *Closing prayers*

#### INVITATION TO INTERCESSORY PRAYER

Pray for genetic counselors, health care providers, and parents who struggle to understand what is best to do for their children, born and unborn.

#### PRAYING WITH THE TRADITION

Gracious and holy God, give us diligence to seek you, wisdom to perceive you, and patience to wait for you. Grant us, O God, a mind to meditate on you, eyes to behold you, ears to listen for your word, a heart to love you, and a life to proclaim you through the power of the Spirit of Jesus Christ, our Savior and Lord. Amen.

*(from Evangelical Lutheran Worship, page 76)*

# Genetic Engineering in Agriculture: How will we be fed?

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

Blessed are you, Lord God of all creation. You have called us out of darkness into light. Open our eyes to your presence; open our ears to your call; open our hearts to your love. Creator and preserver of all, may we work for you. Lover of all, may we love with you. Giver of all, may we give like you, in Christ's name. Amen.



### HEARING THE WORD

Ezekiel 34:20-31

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

The use of genetically engineered crops, animals, and microbes in agriculture presents promises and perils. Scientists, farmers, agribusiness representatives, activists, policy makers, and food eaters hold a variety of different, complex, and even mixed perspectives on how to promote the promising aspects and prevent the perilous ones. Activists on competing sides of the issues produce strongly worded position statements that may help to inform the dialogue, but may also serve to mislead and misinform. To promote debate and discernment, this session introduces some of the key issues that shape people's perspectives on the promises, perils, and controversies.



### Real life stories

1: In 1998, Mr. [Homan] McFarling bought 1,000 bags of genetically altered soybean seeds, and he did what he had always done. [He saved part of the harvest and replanted the seeds.] But the seeds, called Roundup Ready, are patented.

When Monsanto, which holds the patent, learned what Mr. McFarling had sown, it sued him in federal court in St. Louis for patent infringement and was awarded \$780,000. The company calls the planting of saved seed piracy, and it says it has won millions of dollars from farmers in lawsuits and settlements in such cases. [...] Mr. McFarling, 61, [said] he will be forced into bankruptcy and early retirement. "It doesn't look right for them to have a patent on something that you can grow yourself," he said. Janice Armstrong, a Monsanto spokeswoman, said the company invested hundreds of millions of dollars to develop the seed. "We need to protect our intellectual property so that we can continue to develop the next wave of products," she said. <sup>1</sup> [Note: Farmers do sign a contract stating that they will not save the resulting crop for seed.]

2: On the island of Hawaii, on what had been acres of withering, disease-infested plants, farmers this summer are walking among rows of lush green trees, harvesting the world's first crop of genetically engineered papayas. Designed with a gene that allows them to withstand the papaya ringspot virus—an incurable disease that ruins fruit and



God's concern for God's people is always for our vocation to be fruitful and multiply in safety.

When have you experienced our country receiving "showers of blessing" after a difficult national time? Eze. 34:26)

*Genetic engineering* refers to the use of recombinant DNA to modify the genetic structure of plants, animals, and microbes. Techniques include: altering the genetic code to turn on a latent genetic trait or turn off an active one, inserting genetic fragments from one species into recipient organisms, and the cloning of adult cells from mammals. The altered DNA thus becomes part of the recipients' genomes, leading those organisms to express new characteristics and to pass along the altered DNA to offspring. *Agricultural biotechnology, transgenics, and genetic modification* are other terms commonly used to refer to this process.

can sicken trees to the point of killing them—these genetically modified plants are already being credited with saving an industry that was on its way out. [...] “This industry was dying,” said Emerson Llantero, manager of the Papaya Administrative Committee, a research and marketing group supported by papaya farms, most of which are small, family operations of 10 to 20 acres. The new papaya, he said, is a second chance for growers.<sup>2</sup>

3: A new study shows that genes from genetically engineered grass can spread much farther than previously known, a finding that raises questions about the straying of other plants altered through biotechnology and that could hurt the efforts of two companies to win approval for the first bioengineered grass. [...] Monsanto and Scotts have developed a strain of creeping bentgrass for use on golf courses that is resistant to the widely used herbicide Roundup. The altered plants would allow groundskeepers to spray the herbicide on their greens and fairways to kill weeds while leaving the grass unscathed. But the companies’ plans have been opposed by some environmental groups as well as by the federal Forest Service and the Bureau of Land Management. Critics worry that the grass could spread to areas where it is not wanted or transfer its herbicide resistance to weedy relatives, creating superweeds that would be immune to the most widely used weed killer. The Forest Service said earlier this year that the grass “has the potential to adversely impact all 175 national forests and grasslands.”<sup>3</sup>

4: *Cracking the Code of Life*, Segment 15: Genetic Modification

## About genetic engineering in agriculture

Genetic engineering (GE) was introduced in the early 1970s, when Stanford University scientists Stanley Cohen and Herbert Boyer developed methods for cloning DNA fragments and for transferring DNA fragments from one chromosome to another. One of the first organisms altered with this new technology was a bacterium genetically engineered to consume crude oil. In 1980, the Supreme Court ruled, in *Diamond v. Chakrabarty*, that the inventor of this organism could be granted a utility patent, the first time that such a patent was extended beyond inanimate objects to a living organism. (A discussion on patenting and genetics may be found in Session B7: Patenting genes.) Since then, GE has been used to alter mice to facilitate cancer research, to insert human genetic material into pigs in the hopes of harvesting pig organs for human transplants, and to alter food crops to increase nutrient levels and to produce medicines. There are many other examples of plants, animals, and single cell organisms genetically engineered for medical research, hazardous waste cleanup, and pharmaceutical uses. However, we will focus on the application of GE in agriculture in this session.

Genetic engineering was launched in animal agriculture in the 1980s when scientists used the technique to produce hormones (rBGH), which were injected into cattle to increase milk production. In the mid 1990s, the first GE crop, a tomato variety engineered to delay ripening, became commercially available. Since then, corn, soybeans, cotton, canola, alfalfa, potatoes, sweet corn, papaya, squash, and other crops have been genetically engineered and widely adopted in the U.S. and other parts of the world. At least 23 countries have adopted GE crops, including twelve developing countries. Many other nations, including European and developing nations, prohibit or restrict the use, or require labeling, of GE animals and crops.

Since debuting in the United States in 1996, GE crop acreage has expanded around the globe by 12% per year. As of 2007, the total estimated land in GE crops in the world was 282.4 million acres (about 50% of the land in GE crops is in the U. S.).<sup>4</sup> So far, the vast majority of GE crops are those modified to be herbicide-tolerant, that is, engineered to survive the application of heavy doses of glyphosate herbicides. This enables farmers to kill weeds without killing their crops. Since glyphosate is considered a more environmentally benign herbicide than some of the herbicides it replaced, such as Atrazine, there are environmental benefits. Herbicide-tolerant soybeans, corn, canola, cotton, and alfalfa account for approximately 63% of all GE crop acreage.

Another widely adopted set of GE crops includes those engineered to produce their own pesticide. Pesticide-producing corn and cotton account for 26% of the world’s GE crop acreage. Since the crops produce their own pesticides, farmers are able to reduce

the amount of chemical pesticides they apply to these crops. Additionally, the herbicide tolerance and pesticide production traits can be combined in the same plants, often called “stacking traits.” These stacked traits are becoming more common, accounting for about 19% of GE crop acreage in 2007. In the future, multiple traits may be stacked in a crop.

### Promises and perils

Despite the popularity of GE crops, they are not without controversy. *(For more detail, refer to chart at end of session)* Scientists, activists, policy makers, and farmers in industrialized and developing countries have sharp disagreements over the promises and perils of GE crops.<sup>5</sup> Proponents claim biotech developments herald the next agricultural revolution that promises: (a) to increase yield to alleviate hunger and global turmoil resulting from massive population growth; (b) to address production challenges through the development of new crop traits, including drought resistance crops and plants resistant to pests and fungi; (c) to incorporate higher nutritional values into staple crops; and (d) to reduce environmental damage due to the overuse of chemical inputs.

Those skeptical of GE crops argue that there is insufficient attention given to the perils: (a) that GE crops and animals present risks to human and animal health; (b) that GE crops present risks to the environment by creating tolerance to targeted pests and weeds, and thereby creating super weeds and super pests as well as gene flow to other crops and wild relatives; (c) that the world already produces enough food to alleviate hunger, which results from inequitable distribution, without requiring alternative agricultural production; (d) that agro-ecological production strategies coupled with fairer agricultural production and international trade policies are needed to alleviate world hunger; and (e) that GE agricultural production and distribution have socio-economic consequences that will result in corporate consolidation of the food system, the decline of small farming livelihoods, and the reduction of public participation in the decisions that affect their lives.

### Conditions underlying the controversy

The intensity of the debates is understandable since GE in agriculture affects the pillars of life: the food supply and the environment. As “bread and butter” matters they affect everyone, even though they most immediately affect farm communities and developing nations. The complexities then are not simply about the introduction of a new technology, but involve concerns about human health, international trade, the environment, global corporations, government regulation, the economic wellbeing of farmers and farm communities, and the world food supply. The task is further complicated when distinct groups are unable to agree on what criteria should be used when evaluating promises and perils or even what constitutes a promise or peril.

Technological changes are simultaneously social changes, and not everyone affected by the changes will deem them desirable. Some changes may be more dramatic than others, and the promises and perils of the changes may not always be distributed fairly. Some may benefit from a change at the expense of others. What one person or group calls a promise, another person or group might call a peril. As with the introduction of any new technology, (consider the computer or cell phone) the reach and magnitude of these social changes is impossible to fully understand, although a brief look at recent changes in agriculture may enable predictions of social impacts.

GE in agriculture emerged at the end of a century of dramatic changes in agriculture due to industrialization. Mechanization, chemicals, higher yielding crops, and the concentration and consolidation of agricultural and food production, processing, and distribution have benefitted some and harmed others. The increased productivity of agricultural commodities has been credited with reduced food costs, but it also introduced the problem of surplus production. In a market-based system of production and distribution, a surplus of production leads to a drop in prices for the producers. Thus, as farmer productivity increased, farm numbers dropped along with commodity prices. (There were nearly 7 million farmers in the 1940s, but just over 2 million at the start of the twenty-first century.) Although there are still over 2 million farms, a much smaller number of large



farms account for most of the commodity production. Less than 10% of farms account for over 75% of the value of production. Most of the remaining 90% of farms rely on off-farm income.<sup>6</sup> Livestock and dairy production are mostly concentrated in confined production facilities.<sup>7</sup> These dramatic changes in the agriculture and food system have led social scientists to ask if farming as a family livelihood strategy is becoming obsolete.<sup>8</sup>

## Hunger

Perhaps one of the most contentious claims regarding GE in agriculture is that it is needed to solve world hunger problems. Skeptics of this claim often acknowledge that GE in agriculture might be able to address specific agricultural production problems, such as drought and pest resistance. However, they emphasize that the same problem of oversupply that led to the decline in farm numbers in the U.S. is now a global problem. Subsidized commodities, like corn, rice, and wheat produced in Europe and the U.S., are shipped to developing countries around the world. This may lead to reduced food costs for some, but it also undermines markets for local agricultural production, even in remote areas of the world. By undermining agricultural markets in developing countries, these global commodity chains can undermine farm livelihoods. Undermining farmer viability can in turn create more poverty and hunger.

Although there are cases of localized food shortages, there is no shortage of food in the world. Modern famines tend to be driven more by poverty than lack of available food to consume. For example, the *Times of London* reported in 2006 that Kenya was exporting food during a time of famine.<sup>9</sup> And the *New York Times* reported in 2002, that there were 350 million hungry people in India, even as wheat crops rotted in the field and as crops from past years sat untouched in granaries.<sup>10</sup> Such occurrences have been common since the first modern famine, the Irish potato famine of the 1840s, when a fungus nearly eliminated this primary food source for tenant farmers in Ireland. As Busch notes, “Ironically, during the entire period of the famine, Ireland continued to export grain, meat, and other expensive foodstuffs—in quantities that would have been more than able to alleviate the famine.”<sup>11</sup> The problem was not a shortage of food, but a shortage of political will to modify an economic system in which the productive land was owned by a few who exploited poor tenant farmers to produce commodities for export.

Similar conditions persist today. Professor Mamadou Diawara, a scientist in Mali, compares GE in agriculture to medicines when he states: “We have had antibiotics since 1928. But we still have kids dying daily here from very light infections. The challenge is not technical. It is social and political. It is finding simple solutions on the ground.”<sup>12</sup> The point is that, like medicine, food may be available; however, when more than 2 billion people in the world make less than \$2 per day, they are going to find it difficult to purchase food, even if agricultural yields continue to rise.

Hunger may be caused by political corruption and instability, war, and other factors. However, it is primarily caused by poverty. And perversely, as has already been indicated, the oversupply of agricultural commodities in the world may be causing poverty by undermining the viability of small farmers. Therefore, increasing agricultural production is no substitute for a genuine, global effort to redistribute wealth through education efforts, economic development programs, and fair international trade policies.

A committee of experts and activists from industrialized and developing countries was assembled with the title *The International Assessment of Agricultural Science and Technology for Development*, which was sponsored by the United Nations, the World Bank, and several countries. The committee concluded that, rather than rely on GE, hunger might more effectively be addressed by adopting approaches that simultaneously address social, economic, and environmental challenges including: agro-ecological production strategies to address environmental issues, developing opportunities for poor farmers and rural laborers, integrating traditional and community knowledge into formal knowledge, and creating space for more diverse voices.<sup>13</sup>



## Patents and regulation

Concurrent with the dramatic changes in agriculture over the past century, a small number of large agribusinesses have gained greater market share of the complete production and distribution process: agricultural inputs, commodity buying and processing, and transportation and distribution. And these companies have extended their production, processing, and distribution networks around the globe.

Proponents of GE in agriculture claim that patent protection granted to these companies provides an incentive to investment in the development and distribution of improved crops and animals. Since these large agribusinesses can mobilize substantial financial and intellectual resources in the pursuit of specific goals, the hope is that these companies will bring vigor to efforts to address agricultural problems.

Opponents counter that granting patent protection on agricultural crops and animals provides agribusinesses unprecedented control over the food supply, which may lead to higher prices for consumers and force farmers to purchase seeds and breeding stock, thus undermining the viability of small and medium-sized farmers. Although most parties agree that GE crop technology is a powerful new agricultural tool, the United Nations Food and Agriculture Organization (FAO) contends that important factors, such as patenting of seeds, may generate food insecurity along with any benefits.<sup>14</sup>

The disparate social and economic impacts of technologies, such as GE in agriculture, have led some to question the adequacy of government regulatory processes. As has already been discussed in Session A5, government regulatory agencies rely on three standard criteria to evaluate and approve new products and processes: (1) food safety for human consumption, (2) risks to animals and the environment, and (3) technical efficacy. However, increasingly over the last couple of decades, social scientists, citizen groups, and policy makers have recognized a fourth criterion: the social and economic effects of a product or technology.<sup>15</sup> Many Christians may consider this fourth criterion to be consistent with concerns for justice.

The fourth criterion has been advanced by people who increasingly recognized that the issues of GE in agriculture are not purely technical, but also concern the balance between the different worldviews and values that enter the scene of national regulatory and product approval processes. Assessing the perils associated with GE crops and animals, therefore, becomes a complex problem that is being heatedly debated.

## Christian responsibility for moral deliberation

The ELCA's social statements *Economic Life: Sufficient, Sustainable Livelihood for All* and *Caring for Creation: Vision, Hope, and Justice* offer important resources for evaluating the promises and perils of GE in agriculture. The principles of sufficiency, participation, and sustainability provide resources for critically engaging the conventional wisdom and prevailing political philosophies serving as obstacles to theological and moral reflection surrounding scientific research and new technologies.

Debates about new technologies tend to be shaped by four prominent perspectives: (1) technological developments are synonymous with progress, (2) scientific and technical decisions can be made apart from consideration of social values, (3) a market-place of individuals in pursuit of private gain offers a more efficient means of determining the appropriateness of a technology than a government regulatory body, and (4) moral deliberation on the part of citizens, usually through the mechanism of government policy, is necessary to enhance the common good by ensuring a broad distribution of the promises and perils of new technologies. Sociologists note that the first three perspectives tend to prevail in the U.S. debates. The fourth is more prominent in Europe, but still not dominant.<sup>16</sup>

The lack of emphasis on the promotion of the common good is problematic from a Christian perspective. *Economic Life: Sufficient, Sustainable Livelihood for All* claims that all too often, presuppositions regarding scientific progress, markets, and government regulations inhibit Christians from engaging their vocational responsibility to deliberate and

strive to promote the common good. This would seem to indicate that the dominant institutions of modern society—science, economy, government—are morally empty without a mobilized citizenry committed to moral deliberation.

## Invitation to conversation, prayer, and action



### QUESTIONS FOR DISCUSSION

- Christians may disagree on the promises and perils of a new technology; however, a reasonable starting point for a technological debate between Christians is on the principle of neighbor love. Based on the principle of neighbor love, what conditions need to be met before a new technology can be said to contribute to the common good?
- Are all technologies synonymous with progress? What role can science, markets, government policies and regulations, and individual Christians play in ensuring that the promises and perils of new technologies are distributed fairly?
- How is it possible that what one person considers the promise of a technology another might deem a peril? Can both be right?
- When new technologies are introduced, it is likely that each will bring with it some promises and some perils. How might well-meaning people work to maximize the promises and minimize the perils?
- How does the problem of sin inform a Christian's perspective on unintended consequences from GE in agriculture and precaution?

### *Closing prayers*

#### INVITATION TO INTERCESSORY PRAYER

Pray for farmers, agribusiness representatives, and consumers.

#### PRAYING WITH THE TRADITION

Grant to me, O merciful God, that I might ardently love, prudently ponder, rightly acknowledge, and perfectly fulfill all that is pleasing to you, for the praise and glory of your name. Amen.

(Prayer of Thomas Aquinas, who lived from 1225 to 1274)

## Genetic Engineering in Agriculture

	PROMISES	PERILS
CROPS	<ul style="list-style-type: none"> <li>• Resistance/tolerance to disease, pests, herbicides</li> <li>• Increased yields</li> <li>• Improved nitrogen fixation</li> <li>• Tolerance to drought, frost, and other environmental stresses</li> <li>• Reduced need for fertilizer and pesticides/herbicides</li> <li>• Reduced labor and input costs</li> <li>• Faster than traditional plant breeding</li> <li>• Produce pharmaceuticals</li> </ul>	<ul style="list-style-type: none"> <li>• Reduced biodiversity</li> <li>• Unforeseen consequences of mixing genes across species</li> <li>• Creation of resistant weeds and pests (super weeds and super pests)</li> <li>• Farmers unable to replant saved seed</li> </ul>
ANIMALS	<ul style="list-style-type: none"> <li>• Increased hardiness and productivity</li> <li>• Disease resistance with fewer antibiotics</li> <li>• Improved disease diagnosis and treatment</li> <li>• Better yields of meat, eggs, and milk</li> <li>• Faster than traditional animal breeding</li> </ul>	<ul style="list-style-type: none"> <li>• Reduced genetic diversity</li> <li>• Unforeseen consequences of mixing genes across species</li> <li>• Inhumane treatment of animals</li> <li>• Creation of resistant animal diseases</li> </ul>
CONSUMERS	<ul style="list-style-type: none"> <li>• Enhanced taste and quality</li> <li>• Improved nutritional content</li> <li>• Longer shelf life for fruits and vegetables</li> </ul>	<ul style="list-style-type: none"> <li>• No labeling in many countries</li> <li>• Limited regulatory capacity in many developing countries</li> <li>• Food safety concerns (allergens)</li> <li>• Long-term effects not known</li> <li>• Mixing genes among species objectionable to some</li> <li>• Loss of food if devastated by resistant disease or pests</li> </ul>
ENVIRONMENT	<ul style="list-style-type: none"> <li>• Reduced chemical usage</li> <li>• More benign herbicides and pesticides</li> <li>• Natural waste management</li> <li>• May enable more efficient food processing techniques, thus reducing energy use</li> </ul>	<ul style="list-style-type: none"> <li>• Gene flow to wild relative through pollen drift</li> <li>• Unintended consequences</li> <li>• Farmer liability for unforeseen consequences</li> </ul>
SOCIETY	<ul style="list-style-type: none"> <li>• Higher yields increase global food supply</li> <li>• Less water pollution from less chemical usage</li> <li>• More efficient use of land resources</li> </ul>	<ul style="list-style-type: none"> <li>• Higher yields exacerbate agricultural commodity oversupply, leading to lower farm income</li> <li>• Hunger or famine created by lack of alternative varieties if GE plant or animal destroyed by pest or disease</li> <li>• Bio-piracy: industrialized nations exploiting resources of developing countries</li> <li>• Increasing dependence on scientific expertise over farmer knowledge and skills</li> <li>• Few, large companies control the world food supply</li> <li>• Profits concentrated in wealthier nations</li> </ul>

## Endnotes

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- 4 Clive James, *Global Status of Commercialized Biotech/GM Crops*, ISAAA, Ithaca, New York, 2007. [www.isaaa.org/Resources/Publications/briefs/37/executivesummary/pdf/Brief%2037%20-%20Executive%20Summary%20-%20English.pdf](http://www.isaaa.org/Resources/Publications/briefs/37/executivesummary/pdf/Brief%2037%20-%20Executive%20Summary%20-%20English.pdf)
- 5 Erik Stokstad, 2008, "Dueling Visions for World Hunger." *Science* 319(March 14): 1474-1477.
- 6 Robert A. Hoppe, Penni Korb, Erik J. O'Donoghue, and David E. Banker. 2007. *Structure and Finances of U.S. Farms: Family Farm Report, 2007 Edition*. USDA: Washington, DC.
- 7 Terence J. Centner. 2004. *Empty Pastures: Confined Animals and the Transformation of the Rural Landscape*. Urbana, IL: University of Illinois Press.
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- 11 Lawrence Busch. 2000. *The Eclipse of Morality: Science, State, and Market*. New York: Aldine De Gruyter. p. 100.
- 12 Tom Knudson, Edie Lau, and Mike Lee. "Seeds of Doubt: Mali's People Reap No Reward from Cloned Wild-Rice Gene." *Sacramento Bee*. June 6, 2004. [www.sacbee.com](http://www.sacbee.com).
- 13 Erik Stokstad, 2008, "Dueling Visions for World Hunger." *Science* 319(March 14): 1474-1477.
- 14 Food and Agriculture Organization. 2004. *The State of Food and Agriculture*. Agricultural Biotechnology: Meeting the Needs of the Poor? (Rome: FAO).
- 15 William B. Lacy. 2000. "Agricultural Biotechnology, Socioeconomic Issues, and the Fourth Criterion." (pp. 77-89) In Thomas J. Murray and Maxwell J. Mehlman *Encyclopedia of Ethical, Legal, and Policy Issues in Biotechnology*. John Wiley & Sons, Inc.
- 16 D.L. Kleinman and A.J. Kinchy. 2003. "Why Ban Bovine Growth Hormone? Science, Social Welfare, and the Divergent Biotech Policy Landscapes in Europe and the United States." *Science as Culture* 12(3), 375-414.

# Stem Cell Research and Therapy: What should we do?

## Gathering

### HYMN

Suggested hymn: *LBW 360/ELW 610* "O Christ the Healer, We Have Come"; for other suggestions, see page 119.

### PRAYER

We give ourselves to you, O Lord. We give our hopes to you. We give our love to you. We give our fears to you. Let your love set us free. You give yourself to us, O Lord. Let us abide in you as you abide in us through Christ our Lord. Amen.



### HEARING THE WORD

Mark 4:1-9

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

The purpose of this session is: (1) to offer an overview of the state of stem cell research today; (2) to identify the key ethical issues in the debate; and (3) to facilitate your engagement with stem cell issues. By exploring these issues from a variety of perspectives, you will gain a deeper understanding of what is at stake in this controversy. Also, you will come to understand why you hold the views you do and why equally informed, conscientious Christians may make different judgments.



### Real life stories

1. Since 1998, when investigators at the University of Wisconsin announced they had successfully isolated and cultured human embryonic stem cells, reports of new developments in stem cell research have appeared frequently in the media. Some people greet these reports with excitement because they see great promise for the development of revolutionary new treatments for devastating diseases. Others see peril and are dismayed by what they regard as callous disregard for the dignity of developing human life.

The controversy concerning stem cell research has become political as well as ethical. Since August 2001, when President Bush announced his administration's policy restricting federal support to research on existing stem cell lines, Congress has twice adopted—and the President has twice vetoed—legislation to expand federal funding. State legislatures, popular referenda, and candidates in two presidential elections have taken positions for or against various types of stem cell research. How should we, as Lutheran Christians, view stem cell research—as promise, as peril, or as a mixture of both?

2. Watch NOVA Science NOW segment online regarding stem cells (aired 2005) [www.pbs.org/wgbh/nova/sciencenow/3209/04.html](http://www.pbs.org/wgbh/nova/sciencenow/3209/04.html)



Even today, the best seed may produce an uneven crop due to difficult soil and environmental conditions.

Why does the Sower keep sowing?

## What are stem cells?

Stem cells are cells that have the ability to generate perfect copies of themselves each time they divide and to continue doing so indefinitely. All other cells have an internal clock that limits the number of times they can reproduce. Skin cells, for example, reproduce fifty times and then they die. The other characteristic that distinguishes stem cells from other cells is that they have the potential to become specialized into more than one type of tissue. Stem cells that can generate many different types of cells are called *pluripotent*. Other stem cells are *multipotent* in that they can become only a limited range of cell types. For example, blood stem cells can become red blood cells, white blood cells or platelets but nothing else.

Understanding these processes and the signals that direct development holds enormous potential for medicine. Any disease involving the death of cells (e.g., Alzheimers, Parkinsons, hepatitis, and diabetes) is a candidate for a stem cell therapy. Other diseases and conditions that might be treated with stem cells include paralyzing spinal cord injuries, stroke and brain trauma, heart disease, cancer, HIV/AIDS, multiple sclerosis, diseases of the blood, bone, and cartilage. The basic idea would be to replace the patient's dead or malfunctioning cells with new cells generated by transplanted stem cells. Obviously, the number of people who have or will develop one of these diseases or conditions is staggering. That is why stem cells have been called "the Holy Grail" of medicine.

Stem cells used in research come from a variety of sources; some, but not all, of which are highly controversial. Initially, *pluripotent* stem cells came either from embryos created by in vitro fertilization clinics but no longer needed for infertility treatment (so called "surplus embryos") or from fetal tissue obtained from terminated pregnancies. A third source is to use somatic cell nuclear transfer (the technique used to create Dolly, the cloned sheep) to create an embryo that would be genetically identical to the donor of the somatic cell. The stem cells derived from the embryo after five to seven days of cell division could be transplanted back into the donor without any histological incompatibility or the need for immunosuppressant drugs. This method (also known as "therapeutic cloning" or "cloning for research") has yet to be done in humans. As in the case of using surplus embryos, the process of obtaining stem cells destroys the embryo. But here, the embryo has been created expressly for the purpose of deriving stem cells.

Other sources of stem cells are less controversial. *Multipotent* stem cells can be found in various types of tissue (e.g., umbilical cord blood, bone marrow, and skin) and do not require the destruction of an embryo. These *multipotent* stem cells are called adult stem cells because they are the type of stem cell found in the adult organism and are more specialized than the *pluripotent* stem cells found in the embryo. For example, the wisdom teeth of adolescents (routinely removed for orthodontic reasons) contain a large amount of adult stem cells that are very similar to embryonic stem cells and can be turned into brain, bone, and muscle cells. While adult stem cells are generally thought to be less useful medically than *pluripotent* embryonic stem cells, the fact that they are already specialized may be advantageous in certain clinical applications. Adult stem cells have started down the path toward becoming the type of cell needed by the patient, whereas embryonic stem cells could behave erratically and actually harm the patient. Adult stem cell therapies have already proven successful in the treatment of sickle cell anemia and leukemia.

Recent research suggests that it may be possible to obtain embryonic stem cells or similarly *pluripotent* stem cells without destroying viable embryos. Research is under way using parthenotes (unfertilized eggs that can be induced to start dividing but could never develop the placenta needed for gestation). Another method involves the same process used in assisted reproduction programs to assure that an embryo created *in vitro* (in glass) is genetically healthy before it is implanted. While the procedure involves risk to the embryo, there may be little, if any, additional risk if the biopsied cell (called a "blastomere") were also used to generate stem cells. Also in January 2007, scientists reported that stem cells similar to embryonic stem cells had been found in amniotic fluid. None of these procedures involves creating and then destroying embryos, but they would generate stem cells with a genotype different from that of the patient who would receive them.



One way of acquiring *pluripotent* stem cells (identical to the patient's) might be to make a cloned embryo using an adult cell nucleus from the patient, but only after the nucleus and/or the egg into which it will be fused have been altered so that the newly constituted cell will, from the outset, lack the integrated unity and developmental potential of an embryo, and yet will nevertheless possess the capacity for a certain limited subset of growth sufficient to produce *pluripotent* stem cells.<sup>1</sup> This technique would provide the therapeutic benefit of somatic cell nuclear transfer cloning (a genotype identical to that of the patient from whom the adult cell was taken) without destroying a viable embryo.

That potential therapeutic benefit may be achieved by other means in the not so distant future. In 2007, researchers reported that "they had genetically modified human skin cells to behave like embryonic stem cells. These *induced pluripotent stem cells* were capable of forming all three germ layers both *in vitro*" and in mice whose immune systems had been suppressed.<sup>2</sup> This raises the hope that one day a patient could be treated with *pluripotent* stem cells derived from her own skin cells.

Each of these research programs has its skeptics and detractors, and the scientific and bioethical literature is full of vigorous debate about their relative merits. Time will tell which if any of them will work, but it is a heartening prospect that one day we may be able to at least *pursue* embryonic stem cell cures without doing harm to embryonic human life.

## Ethical issues

### "Playing God"

For some people the very idea of using stem cells amounts to "playing God." By this they mean that the Creator has not delegated to us the authority to "tamper" with genetic material. However, according to a 2004 ELCA Social Policy Resolution, "The human capacity for genetic manipulation should be understood, in principle, as one of God's gifts in the created order to be pursued for the good of all. As with any such gift, it must be used responsibly and tested for its contribution to justice and stewardship."<sup>3</sup> But just what is "the created order" within which we are to act responsibly? Is it static or dynamic, fixed once and for all time or continuously evolving? Is there an essential human nature within the created order to be protected from biotechnological alteration or are we free to re-create and improve human nature? If God created and called the creation "good," maybe we should use our God-given abilities to try to make it even better. The Resolution says that genetic manipulation should be pursued for "the good of all," but what does that mean? Do we have a common determinate understanding of concepts such as "the good" or "the public interest"? And who is included in the "all" whose good is to be pursued? Does it include embryos, fetuses, and future generations? Does it extend to all of our near and distant neighbors on the planet or primarily, if not exclusively, to those of us fortunate enough to have the opportunity to contemplate bioethical matters or possibly to benefit from genetic manipulation in the future? How will the burdens and benefits be distributed?

### Do Good (Beneficence) and Do No Harm (Nonmaleficence)

These two duties are fundamental to the moral life. The teachings of Jesus (including the parable of the Good Samaritan) and Luther's exposition of the Ten Commandments in his *Small Catechism* clearly indicate that we are responsible for the well being of our neighbors. That being the case, how could we not pursue these promising avenues of biomedical research? But at the same time Christian ethics must hold means as well as ends in view, and that requires us to resist the temptation to achieve all the good we can no matter by what means.

In the ELCA Social Statement *Caring for Health: our Shared Endeavor*, the ELCA "commends the important work of medical research and supports investment in its goals of healing afflictions, relieving human suffering, and promoting well being."<sup>4</sup> At the same time, it recognizes that "human beings are still finite" despite the fact that "we live in a culture that often denies death and suffering and places its faith in technology to over-

come them.”<sup>5</sup> The statement calls this faith “unrealistic” and “urges caution about research that expands medical technology based primarily on market pressures.”<sup>6</sup>

Priority should be given instead to research addressing “those medical interventions that are likely to improve substantially the overall health of the general population.”<sup>7</sup> Both Christian love of neighbor (*agape*) and justice require us “to work to promote the health and healing of all people” and “provide access to health care for all people in our society.”<sup>8</sup> Moreover, it’s not enough to advocate universal access. The statement urges us to consider our own “health care decisions within the context of the just distribution of health care resources,” asking not only whether we “are being served as individuals, but also whether anyone is being left behind in the ongoing advance of medical progress.”<sup>9</sup>

Would one or another type of stem cell research benefit the overall health of the general population more than vaccinations, prenatal care for poor women, prevention programs, clean water and air, or universal access to basic health care? Limited budgets require tough choices. The relative costs and benefits of stem cell research must be weighed against other medical research and public health needs. And even as we struggle to relieve suffering and achieve an approximation of justice in our allocation of scarce medical resources, we must recognize that, this side of the kingdom of God, vulnerability to suffering is an ineradicable part of the human condition.

### The Status of the embryo

There is simply no escaping the perennial question of the moral status of the early embryo. Is it our moral equal? Should it be regarded as the weakest and most vulnerable of neighbors deserving our protection, rather than exploitation in the service of others? Or is it just a clump of microscopic cells that may be manipulated, used, and discarded as we see fit?

The ELCA Social Statement *Abortion* addresses this issue but is open to divergent interpretations. The statement maintains that “human life in all its phases of development is God-given and, therefore, has intrinsic value, worth, and dignity.”<sup>10</sup> This could be taken to require us to respect the sanctity of even early embryonic life and to renounce the use of embryos in research. However, the statement goes on to observe that “although abortion raises significant moral issues at any stage of fetal development, the closer the life in the womb comes to full term the more serious such issues become.”<sup>11</sup> This could be taken to warrant a developmental view that would not accord full human status from conception on and might allow the use of embryos in the first few days of their development for research or therapy. Moreover, the statement recognizes that “there are circumstances of extreme fetal abnormality, which will result in severe suffering and very early death of an infant” and “in such cases,...the parent(s) may responsibly choose to terminate the pregnancy.”<sup>12</sup>

Clearly, the statement acknowledges the importance of relieving suffering. Some take this to suggest that it would be permissible to use surplus frozen embryos created but no longer needed for infertility treatment. Since they have no future and will be discarded in any case, shouldn’t we use them to produce medical benefit and relieve suffering?

### A “Slippery Slope” to reproductive cloning?

Another issue is the possible slippery slope from therapeutic to reproductive cloning. The process of creating the embryo is the same, but in the latter case the embryo would be implanted in a woman’s uterus. Reproductive cloning has very few advocates. Many people would support criminalization of reproductive cloning at the present time, primarily for reasons of safety. But what about in the future? Would the acceptance of therapeutic cloning today make it more likely that we will approve reproductive cloning tomorrow? Could a line be drawn and held between therapeutic and reproductive cloning? (Among other things, it would require a law mandating the destruction of living human embryos.) If we do not wish to have the latter, perhaps we’d better not accept the former.

Should we forego the possible benefits of a new technology because we fear we won't be able to control it? To say "yes" may seem too pessimistic about the possibility that reason and good will can make moral distinctions and stand by them. To say "no problem" may seem too optimistic. Doubtless, there is good reason for extreme caution. Prudence dictates regulation and oversight. But prohibition? Even if it were possible, would it be desirable?

## Justice

Even if new sources of *pluripotent* stem cells were to render the question of the moral status of the embryo moot, there remain other important ethical issues to be addressed. For example, how would the embryos for single *blastomere* biopsy be obtained? What inducements might compromise the informed consent of prospective donors? Would it be fair to donors (or the fetus they desire) if changes in the usual prenatal genetic diagnosis procedure were to affect the accuracy of the test or diminish the likelihood of a successful pregnancy?<sup>13</sup> If the altered nuclear transfer technique works, there would be a huge demand for eggs. Could it be met without endangering and exploiting poor women in our own country and around the world? (The international black market in kidneys should be a warning.) And who would be able to benefit from stem cell therapies? Only the wealthy or the well insured? Would the stem cell banks be set up so as to serve all of the ethnic groups in our society or just those of European ancestry? What public policy measures might insure fair "biological access," to say nothing of economic access, to the new therapies?<sup>14</sup> Should we continue to provide commercial patent protection to embryonic stem cell "inventions" that might inhibit medical research and make stem cell therapies too expensive for all but the wealthy? These are the sort of emergent ethical issues that we need to address and address quickly before exploitative and unjust practices become the norm.

The burdens and benefits of stem cell research are far too important to be left to the scientific, medical, or business communities alone. Religious communities should engage these issues, bringing to bear the moral convictions and critical resources of their faith traditions. Consider how the notion of justice in ELCA social statements could help us here. (See session A4.)

## Resources for faithful engagement

Having been introduced to the ethical issues, it is time to consider your own moral judgments concerning stem cell research. To a great extent, your moral judgments will depend upon how you frame the issues. A recent article in *The Lutheran* identified three such interpretive frameworks.<sup>15</sup>

The first is the *medical benefits framework*. Looking at the issues in this way focuses our attention on the potential therapeutic benefits of stem cell research. The practice of regenerative medicine (based upon stem cell research) could benefit millions of people whose lives are burdened, if not threatened, by a host of serious diseases. When the question is framed in this way, it's hard to avoid the conclusion that Christian love of neighbor (*agape*) requires the relief of suffering whenever the opportunity arises.

Of course, the question of stem cell research can be framed differently. Suppose one were to approach it from the perspective of an *embryo protection framework*. Within this frame, embryos are regarded as the weakest and most vulnerable of neighbors. Their lives are worthy of respect and protection no less than our own. On this view, Christians cannot be indifferent to their destruction. Even when embryos have been placed in harm's way by the prior actions of others and are destined to be discarded in any event, Christians should resist the temptation to exploit their vulnerability for someone else's benefit.

Still others view the issue of stem cell research in terms of a *nature protection framework*. Here the focus is on protecting human nature from biotechnological alteration. Those who hold this view believe that some types of stem cell research tempt us to move beyond the traditional practice of medicine in the service of life and health within the created natural order toward a project of unlimited self-modification. Such over-reaching blurs the distinction between the creature and the Creator and compromises human dignity. When

we attempt to be more than human (to “play God”), we risk objectifying ourselves to the point that we become less than human.

As you begin to make your own moral judgments about various types of stem cell research, which (if any) of these three approaches seems to you to be the most appropriate way to frame your critical reflection? Notice that, as with any interpretive framework or lens, some things are highlighted while others are obscured. For this reason, should we try to examine the topic using bifocal or trifocal lenses that might afford the most acute and comprehensive vision? Or are the frameworks simply incompatible?

## Invitation to conversation, prayer, and action



### QUESTIONS FOR DISCUSSION

- Within which ‘framework(s)’ would you view the issues concerning stem cell research? Why?
- Are frozen spare embryos “neighbors” and, if so, might it be acceptable to sacrifice some of them for the benefit of many other neighbors? Explain.
- Is it realistic to think that cloning for research (“therapeutic cloning”) could be adequately regulated? Why or why not?
- Would therapeutic cloning inevitably be a first step down the “slippery slope” to reproductive cloning? Why or why not?
- Who is likely to benefit from the therapeutic applications of stem cell research?
- Who may be exploited in the process?
- Of which types of stem cell research do you approve or disapprove?
- If there were a referendum in your state to commit public funds for the promotion of embryonic stem cell research, how would you vote? Explain.

### Closing prayers

#### INVITATION TO INTERCESSORY PRAYER

Pray for those who long for new life, those who wait for new treatment options, and those who work to discover and utilize the gifts of God’s creation.

#### PRAYING WITH THE TRADITION

Eternal light, shine in our hearts. Eternal goodness, deliver us from evil. Eternal power, be our support. Eternal wisdom, scatter the darkness of our ignorance. Eternal compassion, have mercy on us; that with all our heart and mind and strength, we may seek thy face and be brought by thy infinite mercy to thy holy presence, through Jesus Christ our Lord. Amen.

(Prayer of Alcuin, who lived 735 to 804)

### Additional resources

Ted Peters, Karen Lebacqz and Gaymon Bennett, *Sacred Cells? Why Christians Should Support Stem Cell Research*, Rowman & Littlefield Publishers, Inc., 2008.

Michael Ruse and Christopher A. Pynes, *The Stem Cell Controversy*, 2<sup>nd</sup> ed., Prometheus Books, 2006.

Brent Waters and Ronald Cole-Turner, *God and the Embryo: Religious Voices on Stem Cells and Cloning*, Georgetown University Press, 2003.

## Endnotes

1 William B. Hurlbut, Robert P. George, and Markus Gompe, "Seeking Consensus: A Clarification and Defense of Altered Nuclear Transfer," *Hastings Center Report*, 36:5 (2006), 43.

2 Insoo Hyun, "Stem Cells From Skin Cells: The Ethical Questions," *Hastings Center Report*, 38:1(2008), 20-22.

3 ELCA Social Policy Resolution on Genetically Modified Organisms in the Food Supply (2004), p. 4.

4 *Caring for Health: our Shared Endeavor*, Evangelical Lutheran Church in America, (2003), 17.

5 *Ibid.*, 1.

6 *Ibid.*, 17.

7 *Ibid.*

8 *Ibid.*, 18.

9 *Ibid.*, 22.

10 *Abortion*, Evangelical Lutheran Church in America, (1991), 2.

11 *Ibid.*, 7.

12 *Ibid.*

13 Kathy Hudson, "Embryo Biopsy for Stem Cells: Trading Old Problems for New," *Hastings Center Report*, 36:5 (2006), 51.

14 Ruth R. Faden, Liza Dawson, Alison S. Bateman-House, *et al.*, "Public Stem Cell Banks: Considerations of Justice in Stem Cell Research and Therapy." *Hastings Center Report*, 33:6, 13-27. It is also available in Michael Ruse and Christopher A. Pynes, *The Stem Cell Controversy* (Amherst, NY: Prometheus Books, 2006) 199-222.

15 Ted Peters, "Stem Cells: A Moral Question?," *The Lutheran*, January 2008, 17-18.





# Gene Patents: Are they blessings or curses?

## Gathering

### HYMN

(See hymn suggestions on p. 117)

### PRAYER

Blessed are you, Lord God, Creator of all. You have called us out of darkness into your light, into Christ's light. Let his presence bless and guide us this day, that we may share his light and walk before you as children of light to be a blessing to others, through the power of the Holy Spirit. Amen



### HEARING THE WORD

Genesis 12:1-7

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

This session explores the complex matter of patenting genetic inventions or discoveries. It connects this issue to the biblical idea of blessing and curse, and asks how such patents could be blessings or curses, and for whom. Who are the winners or losers when genes are patented? This session is built around a fictional instance regarding a malaria vaccine, and you will be invited to put the ideas of the session to use discussing this scenario. The session first covers the contemporary significance of gene patents, how genes came to be patented, and the advantages and disadvantages of genetic patents. It then widens the focus to discuss genetic patents in terms of developing countries and international trade. The final set of reflections raises some biblical themes that can help us consider ethical issues in the use of gene patents and in patent laws and regulations.



### Real life stories

1. Malaria vaccine and patents<sup>1</sup> (An illustration for discussion)

Malaria is a serious and sometimes fatal disease caused by any of four parasites which are transmitted by bites from *Anopheles* mosquitoes.<sup>2</sup> Because the human body acquires antibodies to malaria parasites from repeated exposures, there is an intensive search to develop a vaccine to boost immunity to the disease.<sup>3</sup>

Imagine that a botanist has learned of a plant used to treat fevers by a fictional tribe we will call the Bomeko in a central African country. A traditional healer tells her that a substance he derives from the plant shortens both the severity and the length of malarial attacks. He shows the curious botanist how he processes the plant and gives her a sample of both the substance and the plant for study in her lab back in Ohio.

Through lab study, the botanist discovers how the compounds in this plant tend to stimulate certain parts of the human immune system that respond to the malaria parasites. Working with a plant geneticist and an immunologist, the botanist creates a research



God's call to Abraham is set in the context of a broken and divided humanity. The call directs Abram and Sarai to leave home and journey into unfamiliar territory on the basis of a promise so that God may bring blessing through the outcome.

Abram's lineage leads to Christ in the Gospels and St. Paul's epistles. What if Abram did not respond positively to God's blessing and instruction? How might the world be a different place?

team to identify what sections of the plant's DNA produce these compounds. Further, after painstaking years of work, they determine that by altering certain sections of the plant's DNA, the plant can produce a compound with a stronger stimulus to the immune system. It now seems possible to develop a malaria vaccine by genetically altering the African plant, purifying the effective compound in large quantities, and providing a way to deliver it safely as a vaccine.

The research team is elated but also daunted. They wish to share their discoveries but also believe it is necessary to patent the processes and the altered DNA of this plant. Why? They know that it will take many years yet and will cost huge sums of money to accomplish and test. The government required testing for clinical use involves demonstrating that the compound is safe and effective in animals. If that is successful, extensive testing follows to determine if it would be safe in people—without unintended side effects—and to find an effective dose. Only at that point will it become possible to market their product.

As they sit down to discuss next steps, there is so much to consider.

2. *Cracking the Code of Life*, Segment 8: "Who Owns the Genome?" (Begin at 45:44 and run to 52:43) and (Optional) Segment 9: "The Business of Science" (Begin at 52:44 and run to 57:41)

## The basics about patents

### The significance of patented genetic knowledge and products today

Should the research team and their university patent their discovery? Why are we talking about patents on living things at all? If they do patent it, do they owe the Bomeko people anything? Is it ethical to patent something that could help so many people, especially those who are so poor? If so, how could they responsibly use a patent to develop a vaccine? How could the people who need it afford it? Who would really benefit from it and be blessed? Who could be harmed by it and be cursed?

Science is now developing the means for a profound understanding of the genetic basis of all earthly life that give human beings both unprecedented power over life and new levels of responsibility for it. The decoding of the human and other genomes makes possible scientific study of how the various parts of these genomes function in each kind of creature. The more we understand how parts of these genomes work, the more we may eventually be able to treat diseases with genetic basis, and develop the potentials of crops, livestock, or other organisms for the benefit of human beings, other creatures, or the environment. Gene patents will play a significant role in how we use our unprecedented power and how we exercise these new responsibilities.

Gene patents both benefit patent holders and make a discovery available to others. At the same time, they can be used to block important genetic research, to prevent competition in the marketplace between products, or simply to earn income through licenses. For instance, those who use patents in research usually must pay a licensing fee. Consumers who buy patented products pay more for them, and consumers who are poor may be unable to afford them. While these matters are complex, there are several key and understandable features that give shape to the basic issues.

### What is a patent? And how is one obtained?

Patents are a government created<sup>4</sup> property right that regulates relationships among people over inventions.<sup>5</sup> They apply not only to the intangible *idea* the inventor has or any *concrete product* that someone makes from that idea, but also to *processes* for research or manufacture. Patent offices award these rights to individuals or to corporations for something they have invented which meets certain criteria in a formal application. Although details differ among countries, generally an invention or process must be *something new, not obvious, useful* and *adequately disclosed* so that others can recreate it or put it into practice.<sup>6</sup>

A patent entitles the right-holder exclusive or monopoly rights to their idea and—other conditions permitting—the right to make, use, license, or sell the invention or process for a length of time, usually 20 years. Patents are given as an inducement to innovation in return for disclosing the details of the invention. This allows others to use and learn from it, subject, of course, to not violating the patent holder's rights.

### Why genes can be patented—the legal background

The patenting of genes and genetically modified organisms is a recent development. Although it has been possible to get a special kind of patent on a plant variety in the United States since 1930, generally patent offices have declined to award patents for living things on the grounds that they are found in nature and were not invented. Genetics helped to change that.

In 1980, the U.S. Supreme Court ruled, in a landmark patent case known as *Diamond v. Chakrabarty*,<sup>7</sup> that a genetically engineered bacterium could be patented. The U.S. Patent and Trade Office argued that the bacterium was a living thing and that the U.S. Congress had expressly authorized the granting of patents for some plants, but not bacteria. The Supreme Court ruled five to four, however, that the Federal statute, which defined a patentable invention as “any new and useful process, machine, manufacture, or composition of matter,”<sup>8</sup> allowed the patent because the bacterium was “a new and useful composition of matter.”

Today, under United States law, patents may be awarded for genetically modified plants and animals, as well as for: genes whose functions are known, gene fragments, sequences of DNA called single nucleotide polymorphisms (known as SNPs), genetic tests, proteins encoded by genes, and stem cells.<sup>9</sup>

### Differing interpretations and pros and cons

There is a lively conversation underway about the pros and cons of patenting genetic material and genetic processes. Proponents and opponents make a number of arguments for their positions which should be noted, even though space is too short to do them justice (see sidebar). Much of the disagreement over patenting genetic material and processes depends on which of three conflicting evaluations of genetic patents is being argued:

Patents are necessary as an inducement and reward for innovation, to encourage sharing of technical knowledge, and to bring needed or advantageous genetic technology to address human problems and problems in the environment.

Patents are unrelated to innovation, may not promote the sharing of technical knowledge, sometimes threaten the resource base of people in developing countries, rob traditional people of their communal knowledge, and are an unjustified grant and enforcement of monopoly power for large corporations at the expense of others, including the poor.

Patents are a potentially useful inducement to innovation in genetic-based medicine and agriculture for the common good, and a reward to corporate or individual inventors. Patents do not, however, always result in innovation or diffusion of technology that addresses every health or agricultural development need. Nor do patents always result in innovation or technology that people can afford. Problems with the patent system need to be addressed for that potential to be fulfilled. Even if such problems are effectively addressed, not every useful innovation or new technology need be protected by patent.

Not every country agrees with all of these extensions of the patent law. The Supreme Court of Canada, for example, ruled that a genetically engineered mouse developed at Harvard for cancer research could not be patented under Canadian law<sup>10</sup> even though Harvard received a patent for the mouse in the United States.

## Arguments for and against gene patents

ARGUMENTS FOR <sup>11</sup>	ARGUMENTS AGAINST
<p>Gene patents promise or now provide:</p> <ul style="list-style-type: none"> <li>• Genetic tests for inherited conditions or predispositions to disease</li> <li>• Genetic engineering of drugs &amp; vaccines</li> <li>• Genetic therapy for mutated genes</li> <li>• Genetic matching of donors and recipients for transplant organs</li> <li>• Future genetic enhancement of normal human capabilities or characteristics</li> <li>• Genetically modified organisms for agriculture</li> <li>• Genetically engineered pesticides &amp; herbicides</li> <li>• Genetic monitoring of environments</li> <li>• Genetically engineered means to clean up toxic waste</li> <li>• Genetically engineered biofuels</li> </ul>	<ul style="list-style-type: none"> <li>• Society may regard genes mainly as economic commodities.<sup>12</sup></li> <li>• Neither life nor DNA should be owned</li> <li>• Places humanity's common heritage into private hands; all should have free access to it<sup>13</sup></li> <li>• Impedes development of genetic tests and therapies, and makes them too expensive</li> <li>• Genetically engineered therapies too costly for the uninsured and poor in developing countries</li> <li>• Focus is more on royalty potential than on useful products</li> <li>• GMO crops subvert seed-saving, add expense, expose farmers to patent infringement suits</li> <li>• Frequently obtained for defensive purposes and to frustrate other scientific research</li> <li>• Replaces scholarly publication; interferes with the diffusion of new knowledge</li> </ul>

### Genetic patents in the global village

Although much commerce in patented genetic technologies occurs inside national economies, international trade also plays a significant role. Moreover, the sources of some—but not all—genetic material for inventions are in developing countries, and this raises specific issues that are increasingly important.

#### Patents and international trade in genetic technology

The new system of international trade created through the World Trade Organization (WTO) affects gene patents through the Agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS). The TRIPS Agreement became effective in 1995, and is binding on all member states.<sup>14</sup> Three key issues concerning genetic patenting are brought to a head by the TRIPS Agreement.

- First, the agreement requires countries to either establish a patent system or upgrade an existing one to minimum international standards.
- Second, the agreement requires developing countries to enforce patents on traded items, which tends to make products from the developed countries more expensive in the developing countries.
- Third, the agreement may make biotechnology and economic development more difficult and more expensive for developing countries trying to modernize and raise their citizens from poverty.

## Gene patenting, biopiracy, and traditional knowledge

Developing countries regard their plants, animals, and micro-organisms to be part of both their biological resources and their natural and (sometimes) cultural heritage. They frequently are offended when samples are removed from their territory without their permission, and especially when products are brought to market without benefit for their country. The misappropriation and unauthorized use of a country's genetic resources generally is called "biopiracy."<sup>15</sup>

Indigenous people of developing countries often live on the social and economic margins of their own societies, far from the halls of power in its National Assembly or the WTO. The plants and animals they depend upon for their livelihood, their traditional medicines, and their cultural or religious festivals are important parts of their way of life, culture, and identity as a people. They pass all this traditional knowledge<sup>16</sup> on to new generations. South African theologian Puleng Lenka Bula described the attitude of indigenous people this way:

The TRIPS agreement only recognizes knowledge that is associated with commerce and grants rights to those applying this knowledge. It undermines knowledge residing in communities, such as indigenous/traditional knowledge, which is generally used to nurture the earth, humanity and other creatures. Such knowledge cannot be subsumed into the market logic. . . . [TRIPS] recognizes, protects, and grants intellectual property rights [such as patents] to the creativity of Northern companies, but in many instances, this is based on indigenous knowledge that has been modified to fit Western ("scientific") [models].<sup>17</sup>

Occasionally, however, indigenous peoples have successfully challenged biotechnology patents.<sup>18</sup> Sometimes this happens with the assistance of allies.

### Patent law and justice

The challenge, in light of these factors, is to implement practical, effective, accountable, and just ways to assure that the interests of indigenous peoples in their genetic resources are respected in patents and licensing.<sup>19</sup> Toward that challenge there are two important points to be considered.

If a government's goal is to use patents to develop significant innovations that contribute to the social, economic, and ecological wellbeing and health of their people, then criteria for patentability and how patents are administered are important. Stricter criteria for novelty, non-obviousness, utility, and disclosure are more beneficial if they make it more likely that the most significant innovations are patented, and less likely that minor ones or marginal improvements on existing inventions be patented. Similarly, patent systems might be devised to discourage patent holders from creating obstacles to continued research and development.<sup>20</sup>

Beyond the matter of legality, Christians and many others would insist that matters of justice must be represented. Much more would need to be said, but for this session it suffices to note that the ELCA has articulated four relevant principles of justice in its social statements. These four principles include solidarity, sufficiency, sustainability, and participation. (Please see session A4 "Four Principles of Justice," for more on these principals.) These principles are directly relevant when considering:

- how the Bomeko people should benefit from development of the vaccine (*solidarity, sufficiency, participation*);
- whether, how, and where to grow the genetically modified plant (*sustainability, participation*);
- how a pharmaceutical company could develop a vaccine in an economically feasible way (*sufficiency*);
- how to distribute or market and administer the vaccine at an affordable cost to persons or agencies (*solidarity, sufficiency*).

In the discussion at the end of this session, these matters will come into play, but we must touch on several additional biblical and theological points before we are ready to enter that discussion.

### A Thought Experiment on Bioprospecting and Biopiracy

As a thought experiment, imagine how Americans would react if biologists from India removed a nesting pair of American eagles and their eggs from the wild without approval from the U.S. Fish and Wildlife Service. They take the eagles either for breeding experiments to genetically enhance endangered Indian birds of prey in the wild or for commercial breeding for exotic feathers for the Mumbai fashion industry. Let's also imagine that the Indian scientists or businesses involved patented their innovation in India. Now, as a Representative or Senator in the U.S. Congress, compose your floor speech about this issue.

Next, imagine yourself a citizen in a small developing country after you have learned that geneticists from the United States have just patented a drug derived from the genetic material of living things in your country. Compose your floor speech for the National Assembly of this country.

Discuss together what you might say in your speech.



## Christian resources for thinking about patents

Since genetic patents first appeared, some religious and theological objections have been raised against them in principle, but these objections are not uniformly shared.<sup>21</sup> Meanwhile, most governments in the developed world have granted many kinds of genetic patents and integrated them into legal arrangements for international commerce. They are a reality. Christians, then, should also focus our ethical attention on how such patents should be used, and consider how they may possibly promote blessing in the world, and how they may undermine such blessing.

### Dominion—responsibly tending and keeping what God calls “good”

In the Bible, the commands to be fruitful (Genesis 1:22, 28) and bring forth living things (Genesis 1:20, 24) are given to all living creatures, to the waters, and to the earth. Fruitfulness is pictured in the Bible both as an abundant variety of all kinds of robust creatures, and as the eventual appearance of their descendants.

God commands humankind to have dominion over living things and to till and keep the garden (Genesis 1:28; 2:15). These metaphors suggest concerned attention both to small details and to the wellbeing of the individual creatures, as well as to the productive flourishing of the larger whole.

This picture of dominion is not one of domination; it expresses how God cares for the creation. God gives human beings responsibility to be fruitful in their dominion and calls them to act responsibly. If they do, their dominion will fulfill God’s command. God will bless the garden or the river and all the robust, abundant variety in them, for they will be fruitful. And in their flourishing, they will, in turn, bless humankind. (For more on human responsibility vis-à-vis creation, see sessions A2 and A3.)

### The idea of blessing

The abundant variety and robustness of creatures and their descendants, including humankind, which partly results from responsible human dominion, is the *expression* of divine blessing. Blessings flow from God’s potent Word, which gives power to fulfill the commands to be fruitful and exercise responsible dominion, and which promises that, ultimately, our efforts in this regard will be productive of good. Blessing, therefore, is both promise and empowerment, *the essential ground* for being fruitful and exercising dominion. God’s blessings are gifts, mediated through human and non-human agents, empowering those who receive them to “experience and bring forth life, goodness, and wellbeing.”<sup>22</sup>

When God calls Abram in Genesis 12:1-3 and promises to bless him, God declares that Abram is being blessed “so that [he] will be a blessing;” indeed, “in [him] all the families of the earth shall be blessed.” So God’s blessing is important for the whole world.

In Deuteronomy 30:19, God declares to God’s people: “I call heaven and earth to witness against you today that I have set before you life and death, blessings and curses. Choose life so that you and your descendants may live....” It would seem that some of what we do does *not* enable us to “experience and bring forth life, goodness, and wellbeing,” but results instead in *their opposites*, at least for some. Genetics, as a human activity involving moral choices, has the potential to bless or curse.

Our ethical calling, therefore, is this: despite our sin, we must discern what brings forth blessings and what results in curses for human beings and other creatures, and we must work to secure those blessings and avoid those curses. There are many people who, through a responsible use of genetics and biotechnology, could be agents of blessing by bringing improved health, abundance, and wellbeing to humankind. Ironically, these same people might bring a curse upon the land if they do not act responsibly in using the power of genetics to promote life, goodness, and wellbeing *for all* of creation.



## Invitation to conversation, prayer, and action

With these insights now in mind, reread the opening story about the botanist and imagine that you are a member of the research team that wants to responsibly exercise the opportunity they have. Discuss what would be the most responsible way for the research team to proceed as they factor in genetic science, professional work, plant DNA, national sovereignty, and the other aspects discussed above. How can they use what they have learned so that their discovery *may bless* those who suffer with malaria in the future?



### QUESTIONS FOR THE RESEARCH TEAM

- In the illustration about developing a malaria vaccine above, would you recommend the company develop and patent its new vaccine? Why?
- What benefits, if any, do you think the researchers and the pharmaceutical company should agree to provide the Bomeko people?
- What benefits do you imagine they might want for themselves? As you think about this consider the following:
- Should the innovation should be patented or left in the public domain?
- Which of the three views of gene patents above do you personally hold, and why? What are the arguments for and against each view?
- Have you, or someone you've personally known, been blessed or cursed in some specific way by a genetically engineered organism or a genetic innovation? Do you know if it is patented? How do you imagine life would be better (or worse) if this innovation did not exist?
- How would you be able to fund your research and drug approval (and employ all the people to do it) without some of the protection that patents give. What would be the alternative funding sources for "open research?"

## Closing prayers

### INVITATION TO INTERCESSORY PRAYER

Pray for government officials, lawyers, researchers, business people, human rights activists, and all who struggle to understand and implement the right use of genetic patents.

### PRAYING WITH THE TRADITION

We beseech you, O Lord, to grant us your help and protection. Deliver the afflicted, pity the lowly, raise the fallen, reveal yourself to the needy, heal the sick, and bring home your wandering people. Feed the hungry, ransom the captive, support the weak, comfort the fainthearted. Let all the nations of the earth know that you alone are God, that Jesus Christ is your child, and that we are your people and the sheep of your pasture. Amen.

(Prayer of Clement of Rome, who lived c. 96)

## Additional resources

### Print

John H. Barton, "Intellectual Property Rights: Reforming the Patent System," *Science* 287: 5460 (March 17, 2000) p. 1933

Audrey R. Chapman, *Unprecedented Choices: Religious Ethics at the Frontiers of Genetic Science*, (Minneapolis: Fortress, 1999).

Commission on Intellectual Property Rights, *Integrating Intellectual Property Rights and Development Policy* (London, 2002). This is also available online at: [www.iprcommission.org/](http://www.iprcommission.org/)

Celia Deane-Drummond, *Genetics and Christian Ethics* (Cambridge: Cambridge University Press, 2006).

Stephen A. Hansen and Justin W. VanFleet, *Traditional Knowledge and Intellectual Property* (Washington, D.C.: American Association for the Advancement of Science, 2003).

## Web-based

Anonymous, "Patently Problematic," *The Economist*, September 12, 2002 (print edition) online at [www.economist.com/science/](http://www.economist.com/science/) (accessed 3/19/05)

Commission on Intellectual Property Rights, [www.iprcommission.org/home.html](http://www.iprcommission.org/home.html)

National Human Genome Research Institute—Intellectual Property and Genomics, [www.genome.gov/19016590](http://www.genome.gov/19016590)

The Public Intellectual Property Resource for Agriculture (PIPRA), [www.pipra.org/](http://www.pipra.org/)

U.S. Department of Agriculture, Economic Research Service-Intellectual Property Rights, [www.ers.usda.gov/Browse/ResearchProductivity/IntellectualPropertyRights.htm](http://www.ers.usda.gov/Browse/ResearchProductivity/IntellectualPropertyRights.htm)

U.S. Patent and Trade Office, [www.uspto.gov/main/policy.htm](http://www.uspto.gov/main/policy.htm)

World Intellectual Property Organization—Traditional Knowledge, Genetic Resources, and Traditional Cultural Expressions/Folklore, [www.wipo.int/tk/en/](http://www.wipo.int/tk/en/)

World Trade Organization, TRIPS Gateway, [www.wto.org/english/tratop\\_e/trips\\_e/trips\\_e.htm](http://www.wto.org/english/tratop_e/trips_e/trips_e.htm)

## Endnotes

1 This account is completely fictional, however, it highlights the kind of issues involved in genetic research today.

2 The World Health Organization estimates that between 300 million and 500 million new cases occur every year, and about 1 million of stricken people die. It causes severe flu-like symptoms, which if not treated promptly can lead to death. Most of the cases occur in Sub-Saharan Africa and South Asia, although the U.S. reports 1,300 new cases each year. Those most vulnerable to serious illness and death include young children, pregnant women, and travelers from outside malaria-prone areas. [Source: U.S. Centers for Disease Control, [www.cdc.gov/malaria/faq.htm](http://www.cdc.gov/malaria/faq.htm) (accessed 10-03-08).]

3 Background on Centers for Disease Control research into immunity to malaria is available at [www.cdc.gov/malaria/cdcactivities/research.htm](http://www.cdc.gov/malaria/cdcactivities/research.htm).

4 In the United States, this power is established in Article I, Section 8 of the U.S. Constitution: "The Congress shall have power...to promote the progress of science and useful arts, by securing for limited times to authors and inventors the exclusive right to their respective writings and discoveries...."

5 Morris R. Cohen, "Property and Sovereignty," in Cohen, *Law and the Social Order* (New York: Harcourt, Brace, 1933), describes property as a relation among persons with respect to things, p. 45. This means that property is not the same thing as mere possession. A thief may possess my car, but he has no right to own or use it; I do. I have the right to drive it, to lend it to a friend if I want to, or to give it to a charity. But if I am unable to make a succession of payments on my car, the bank that owns the loan contract on my car may legally take possession of it and become its sole owner.

6 John H. Barton and Ezekiel J. Emmanuel, "The Patents-Based Pharmaceutical Development Process: Rationale, Problems, and Potential Reforms," *Journal of the American Medical Association (JAMA)*, 294:16 (October 26, 2005) 2076, citing 35 USC §§101, 102, 103, and 110.

7 *Diamond v. Chakrabarty*, 447 U.S. 303 (1980).

8 35 U.S.C. §101.

9 "Genetics and Patenting," [www.genomics.energy.gov](http://www.genomics.energy.gov) (accessed September 1, 2008).

10 In the case *Harvard College v. Canada (Commissioner of Patents)*, [2002] 4 S.C.R. 45, 2002 S.C.C 76. The Court ruled on the case in a 5-4 decision.

11 These and other possible benefits are listed on the Web site of the U.S. Department of Energy's Office of Science at [www.genomics.energy.gov](http://www.genomics.energy.gov) (accessed September 1, 2008).

12 See Audrey R. Chapman, *Unprecedented Choices: Religious Ethics at the Frontiers of Genetic Science*, (Minneapolis: Fortress, 1999) 151-152, and Celia Deane-Drummond, *Genetics and Christian Ethics* (Cambridge: Cambridge University Press, 2006) 173-175 for discussion of this issue.

13 Pilar N. Ossorio discusses two versions of this argument in "Common Heritage Arguments Against Patenting Human DNA," in *Perspectives on Genetic Patenting: Religion, Science, and Industry in Dialogue*, Audrey R. Chapman, ed. (Washington, D.C.: American Association for the Advancement of Science, 1999) 89-108.

14 Details of the history and development of international trade agreements and some of the issues they raise for intellectual property such as patents are found in John H. Barton, Judith L. Goldstein, Timothy E. Josling, and Richard H. Steinberg, *The Evolution of the Trade Regime: Politics, Law, and Economics of the GATT and the WTO*, (Princeton: Princeton University Press, 2006). The WTO now has 153 member countries. The World Trade Organization Web page about the TRIPS Agreement is at: [www.wto.org/english/tratop\\_e/trips\\_e/trips\\_e.htm](http://www.wto.org/english/tratop_e/trips_e/trips_e.htm). The text of the TRIPS Agreement itself is at: [www.wto.org/english/docs\\_e/legal\\_e/27-trips.pdf](http://www.wto.org/english/docs_e/legal_e/27-trips.pdf).

15 *Integrating Intellectual Property Rights and Development Policy*, 74, and Hansen and VanFleet, 4-5.

16 See *Traditional Knowledge and Intellectual Property*, 3-4, for a discussion of what is meant by the concept of “traditional knowledge.”

17 Puleng Lenka Bula, “Privatizing Property that Belongs to All,” in *Lutheran Ethics at the Intersections of God’s One World*, Karen L. Bloomquist, ed. (Geneva: Lutheran World Federation, 2005) 198-199.

18 See the examples in *Integrating Intellectual Property Rights and Development Policy* 76-78.

19 See *Integrating Intellectual Property Rights and Development Policy* 79-87, *Traditional Knowledge and Intellectual Property*, 21-31, 35-38, 57-64, and “Draft Guidelines on Access and Benefit Sharing Regarding the Utilization of Genetic Resources,” Annex, pp. 2-4, 9-11.

20 John H. Barton, “Rational Limits on Genomic Patents,” *Nature Biotechnology* 18 (August, 2000) 805, “Intellectual Property Rights: Reforming the Patent System,” *Science* 287 (Issue 5460) March 17, 2000, 1933-1934, and “Emerging Patent Issues in Genomic Diagnostics,” *Nature Biotechnology* 939 (2006).

21 For elaboration of the following discussion see Chapman, *Unprecedented Choices*, 125-165, Ronald Cole-Turner, “Theological Perspectives on the Status of DNA: A Contribution to the Debate Over Genetic Patenting,” in Chapman, *Perspectives on Genetic Patenting*, 149-165, Celia Deane-Drummond, *Genetics and Christian Ethics*, 160-190, and Ted Peters, *Playing God?*, 115-141.

22 Terrence Fretheim describes blessing this way: “Blessing is a gift of God, usually mediated through human or nonhuman agents, that empowers recipients to experience and bring forth life, goodness, and well-being, including spiritual and more tangible expressions. God’s blessing is given creation-wide scope from the beginning (Gen 1:22, 28). . . . Through acts of blessing, God provides a life-giving, life-enhancing context for all creatures within every sphere of their existence. As such, blessing belongs primarily (but not exclusively) to the sphere of creation, both originating and continuing creation.” Terrence E. Fretheim, *God and the World in the Old Testament: A Relational Theology of Creation* (Nashville: Abingdon Press 2005) 106. See also Fretheim’s concluding discussion at 269-282 for how he sets blessing in the context of the relational theology of creation he finds in the Old Testament. Fretheim builds on the work of Claus Westermann, *Blessing in the Bible and in the Life of the Church*, Keith R. Crim, tr., (Philadelphia: Fortress, 1978), esp. 4-6, 8, and 15-68. For his comments on Westermann’s work on blessing in the context of Old Testament scholarship on creation, see xii-xiv.



# Enhancing Human Life: Would you like to be better than well?

## Gathering

### HYMN

(See hymn suggestions on p. 119)

### PRAYER

Blessed are you, O Lord. You made the world in your love. You redeemed the world by your love. You sustain the world with your love. May we ever abide in your love, and give ourselves to you and to others in love. Amen.



### HEARING THE WORD

Isaiah 65:13a, 17-25

### DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

## Introduction

### Session summary

This session explores questions of faith and witness around the use of genetic knowledge and technology to “enhance” life. Christians claim a calling to care for the disabled and to heal disease. As disciples of Jesus, we seek to restore wholeness to the brokenness of life. But suppose that new powers over mind and body, today and in the future, allow us to be “better than well” in the sense of improving upon the genetic inheritance that we receive from God through biological parents. Is this a new calling for people and society? If so, what should this mean practically? If we can make people better, do we owe this to future generations?



### Real life stories

#### 1. Life extension now

In an effort to explain the “paradox” that some peoples have a low level of coronary heart disease despite diets high in saturated fats, researchers have been studying the properties of an antibiotic and antioxidant produced by red grapes called resveratrol. Also found in blueberries and peanuts, ingesting resveratrol has been shown to increase the lifespan of yeast, worms, fish, and mice by promoting healthy cell function and by protecting the body against cancer development, which increases in frequency as people age. Research on the life extension properties of resveratrol in humans is currently inconclusive but appears to be one of several promising ways for humans to significantly increase life span. Resveratrol nutritional supplements derived from the Japanese knotweed plant are available for consumption. Assuming that these products are safe and effective, should a person take this supplement? If taking resveratrol is good, what more should a person do in an effort to improve health and extend life?

#### 2. Choosing embryos

Since the late 1970s, *in vitro* fertilization and embryo transfer technology have contributed to thousands of live births and have allowed thousands of individuals and couples



Isaiah sees God’s commitment to creating anew as following God’s rejection of those who have worshipped Fortune and Destiny (Isaiah 65:1-11) and ignored the Almighty. God’s generosity shall be for the faithful, not the idolaters.

How has Christ’s coming changed our view of God’s wrath? Or has it?

Gene therapy is the term used for treating disease by replacing, manipulating, or supplementing nonfunctional genes.

to be parents, who might otherwise not be able to be parents. It has created new social and family arrangements such as gamete donation and surrogate parenting. Since 1989, *in vitro* fertilization and embryo transfer have also allowed a prospective parent or parents to employ new and powerful genetic technologies to screen embryos for certain genetic information prior to implantation in the womb. Today, preimplantation genetic screening can detect sex as well as risk factors for over 100 conditions viewed as disease, such as cystic fibrosis and Huntington's disease. Today, people are likely to seek out such screening in the context of genetic counseling due to family history or prior reproductive experience. In the future, as depicted in the 1997 film *Gattaca*, preimplantation genetic screening could become a routine and expected procedure, coupled with selective embryo transfer for preferred characteristics. Some expert observers think that this trend is inevitable and should be embraced. Others lament a future where parents might seek the "perfect" baby. Is our society on a course toward routine preimplantation genetic screening and embryo transfer? Should a prospective parent or parents seek to give their child as many perceived advantages as possible through these technologies?

### 3. Designing people<sup>1</sup>

If the purpose of medicine is not simply to cure and care for people afflicted by disease but also to improve upon given limits and deficiencies of the body, then preimplantation genetic screening and embryo transfer do not go far enough. Developing "gene therapy" to change the underlying genetic cause of illness or disability is not enough. In addition to reducing and removing the incidence of disease through preimplantation genetic screening or gene therapy, medicine should seek to alter individual human genomes so that they can be both healthy and better than healthy, in a word, "enhanced." In one vision of this future, perhaps 100 years from now, humans will have understandings and techniques that will allow them to add modules of genes for preferred characteristics by adding artificial, auxiliary chromosomes into our present 46. These modules could override or "knock out" certain genes we do not want to be expressed and add or "knock in" certain genes we want to improve our lives. Like computer software that gets upgraded, parents might choose not to pass on the artificial chromosomes that they received from their parents. They could instead use the latest version of auxiliary chromosomes for their child, which might protect better against cancer or increase toleration for heat. Some genetic research today is creating a pathway to such germline genetic intervention. Suppose that this technology could allow people to do more to experience life more richly, to understand it more deeply, to create better, to cooperate well, and to undertake all sorts of other human endeavors more competently and to be more of what people long to be. Should people use genetic technology to pursue this goal?

### 4. Smart drugs

Well before humans might be able to add auxiliary chromosomes to their cells, medicine will give people opportunities to improve on their given genetic constitutions through pharmacogenomics (or pharmacogenetics), the effort to tailor-make pharmaceutical agents to individuals. For various reasons, research dollars invested in this enterprise vastly outpace investments in gene therapy. As understandings of genetic process grow, researchers believe that better medicines attuned to individual genetics are possible. These individualized medicines could have an enhancement effect. Currently, people across the world routinely receive various immunizations to improve resistance to infectious diseases such as influenza or measles or rubella. Immunizations are considered basic and essential treatment. But some observers would say that they are enhancements because people are healthy when they receive a vaccine; their immune systems are strengthened by immunization. Pharmacogenomics would be a more powerful way to improve the body and the mind. With this technology, people could make their own choices about "design," rather than being designed by others in the case of germline enhancement. While scientists work on gene therapy and germline enhancement, should society pursue individualized drugs? How should access be determined?

Pharmacogenetics is the study of genetically-controlled variations in individual responses to drugs or products that use genetic susceptibility as part of the rationale for their use. Pharmacogenetics and pharmacogenomics are essentially the same process even though sometimes distinguished.



## The opportunities and challenges of enhancement

Until the 20<sup>th</sup> century, humans could do relatively little to control disease and death. Western physicians were taught “above all, do no harm” because the body either healed itself or it did not. Physicians cared more than they cured. In the 20<sup>th</sup> century, modern sanitation, improved diets, viral immunizations, and antibiotics did wonders to improve health and to extend life spans. In 1900, average life expectancy in the United States was 48 years; by 2000, it was 78. The advent of the genetics age in the second half of the 20<sup>th</sup> century added little to this change. But after fifty years, genetics-based medicine stands on the threshold of precise and extensive interventions into the body and the mind that could become routine for most people in wealthy societies like the United States. How far and how quickly such changes extend beyond wealthy societies remains to be seen.

With these new powers, human health decisions could involve more than whether to cure diseases through prevention and therapy assisted by genetic knowledge. Thousands of problems with genetic sources will be better understood and powerful new therapies may be available. The knowledge that enables us to understand the genetics of illness and death will also allow us to create life that reflects human design. Increasingly, humans understand how the building blocks of life are arranged and function. Increasingly, humans will face decisions about whether to use this understanding to make life “better” than in the past.

Drawing upon genetic science, should humans seek to enhance or improve the human body in new and different ways? For some time, bioethicists have generally thought about genetic “enhancement” as something different from “therapy” and have generally seen therapy to be less morally complex. Therapy involves efforts to treat recognized diseases or disabilities with a view to restoring or establishing a “normal” or species-typical state of health. If it is morally right for a doctor to prescribe an approved drug with a patient’s informed consent, it follows that this doctor may do well to prescribe a drug tailor-made to the patient’s particular genes, assuming that the technology is safe. Similarly, genetic therapy aimed to address the underlying genetic condition that calls for drugs treatment would be indicated. Pharmacogenomics and gene therapy are new interventions. Yet, from an ethical point of view, they are no different than the therapeutic prescription drugs that people take every day.

Bioethicists often view using genetic technology to improve normal functioning of the body as a different and morally complex intervention. Some view such enhancement as morally questionable, arguing that therapy has greater urgency and standing than enhancement. Recently, a presidential bioethics panel has abandoned the distinction between therapy and enhancement, seeing it as less helpful than some hold in determining right from wrong and good from bad. The distinction depends upon concepts such as “normal,” “health,” and “disease” that are difficult to define. Individual characteristics and capacities vary along a continuum. “Normal” is usually a set or range along this continuum.

For example, suppose that a person believes that she or he was born with poor memory and has access to a drug that improves memory function. Is this therapy or enhancement? How should we classify the routine use of orthodontia in America today? Is this therapy or enhancement? A surgical procedure to treat skin cancer clearly addresses a disease and is therapeutic. What about surgery to improve facial appearance at 50? Many people have such “cosmetic” surgery, believing that enhancement of appearance in response to the aging process is a valid use of medical resources. In place of the distinction between therapy and enhancement, perhaps we should be asking about the proper and wholesome uses of technology. What are good and bad uses of surgery? Perhaps this is the question: in Lutheran terms, what is good for the neighbor?

All four scenarios above present situations where humans face contemporary and future decisions about enhancement made possible by genetic knowledge and technology. The first two illustrate that enhancement opportunities are available today. However, “enhancement” on a large scale with major improvements has yet to be realized. Ingesting resveratrol and preimplantation genetic screening today offer relatively little gain compared

to possible powers of the future. Researchers working on life extension contend that another doubling in lifespan (like the 20<sup>th</sup> century) will require intervention into the genetic sources of aging and death such as cell parts called telomeres which control cell replication and which shorten over time (except cancer cells). Genetic engineering will need to switch off this natural shortening process before humans can live to 160 or more. Until then, people can increase chances of personal longevity by restricting calorie intake, taking certain hormones, and eating antioxidants.

To double human life span for some or for all, society will need to invest huge resources into aging research coupled with some effective delivery system for changing gene function. Taking resveratrol is a personal decision; doubling current life space will require a social decision with certain social consequences. The science and the technology that could enable humans to live until 160 is probably beyond the lifespan of most of us (although some researchers believe that some young people today could live to see a doubling and more of lifespan). A major question, then, is whether society ought to pursue this goal, among other community desires and imperatives. And with this question come further questions of gains, costs, and future consequences.

Similarly, preimplantation genetic screening offers gains today in preventing certain diseases being passed from biological parents to children. As time goes on, this technology may be able to screen for genetic characteristics that parents want to pass along to their offspring, say, eyesight better than 20/20. In both cases, these children could be seen as “improved” over traditional reproduction where the genetic intervention that humans exercise is the decision to procreate with another person. But in this intervention, parents have little to no influence over genetic outcomes.

Despite current limits, preimplantation genetic screening with embryo transfer offers a major change in human reproduction. As the scenario on “designing people” suggests, it would be a necessary feature of germline engineering through artificial chromosomes. Today, preimplantation genetic screening is not routine for several reasons. As with significant lifespan extension, routine use of preimplantation genetic screening would change the way that human beings are conceived and brought into the world. The institution of parenting would change in important respects. Among other changes, parents would experience more decisions and more responsibility. The concept of a “genetic duty” to use preimplantation genetic screening may emerge. It could become normative from the point of view of social approval or medical service access. Such personal and cultural changes are hard to predict, but broad social acceptance of preimplantation genetic screening would change social attitudes, values, and expectations.

The best prospects for enhancing human life will be achieved when genetic science has advanced to the point where we can engage in germline manipulation, perhaps through the insertion of auxiliary chromosomes. The idea of “designer” people will require scientific understanding and societal resources that can only be imagined today. However, recent developments in research and development are giving credence to the view that the “genetic” era has arrived. We live in a time called to consider and to discern whether humans ought to do everything within their powers to make people smarter, healthier, happier, and generally excellent in these and other ways. We already seek these goals through social means such as education and religion. The time has come where humans can employ genetic engineering and other technological developments such as regenerative medicine to seek substantial betterment of the human condition. Should humans do this and how?

## Thinking faithfully about enhancement

As Christians, we seek to live and act in ways that mirror God’s will and actions in the world. Christians seek to love God and to love the neighbor in response to the gracious actions of God upon them. The questions of whether and how humans should enhance life through genetic engineering should be informed by Christian convictions about God’s actions in this world. Christians see a world where God acts in creation, redemption, grace, incarnation, and transfiguration. They see a world that is good but broken and disordered;

they see a world where a gracious and living God seeks to bring the world into harmony with God's purposes.

The response of Christians to this world is disclosed in the life, death, and resurrection of Jesus. In Jesus, Christians see a God who seeks to overcome the brokenness of the world and who promises to overcome even death. The life of Jesus gives testimony to God's special concern for the weak, the sick, and the poor. Jesus calls upon his disciples to do as he does, or as Martin Luther said, "to be little Christs to the neighbor."

Christians have wondered and even debated whether humans can participate faithfully in God's creative and redemptive actions. Some Christians believe that the rare individual, the saint, can do God's will. Others think that the Christian community can be a place where the reign or rule of God occurs. For others, God's intentions can be glimpsed in common morality such as democracy or marital equality. Despite these differences, all agree that humans can participate in God's action in this world. Although judging when they do is difficult, Christians agree that God intends for humans to be dead to sin and alive to God in Christ.

If God seeks to overcome the brokenness and disorder of the world, can humans participate in God's creation and redemption through genetic enhancement? For some Christians, the power of sin coupled with the power of 21<sup>st</sup> century genetics are cause for great concern. Despite God's intentions, sin pervades and distorts all human endeavor, both individual and corporate. While genetic knowledge and technology can be instruments of God's presence in the world, they can be used unjustly and can damage values systems and institutions that sustain human life. By seeking to enhance human life, will we be like Adam and Eve in the garden—refusing to live within the good Creation that God provides? By seeking to enhance human life, will we be saying "no" to God and God's giving and "yes" to our own projects of creation? For some Christians, enhancing human life should be renounced because it embodies the primal sin of Adam and Eve—the sin of pride where humans refuse God's grace and turn away from God, seeking to live by their own judgments and powers.

This sense of sin may result in an absolute rejection of enhancing human life. It may result in a deeply cautious approach that errs on the side of therapy and rejects enhancement because horrible results could occur and because humans do not know enough to risk such harm. Either response puts Christians at odds with the typically positive appraisal of "technology" in American society. This cultural outlook does not deny that technology creates problems, but the problems engendered by technology can be solved by technology, and the benefits of change generally outweigh the costs. In its strongest terms, this outlook sees technology taking us toward utopia.

For some Christians, there is a middle position between pessimism and utopianism. On this view, the power of sin cannot be dismissed and forgotten. But neither can the power of Jesus to guide the right use of genetic technology. While not dead to sin, Christians can be alive to Christ sufficient to see and to strive for uses of genetics that further discipleship of Christ. If human technology is guided by the ethics of Jesus, perhaps it can be said that genetic enhancement can participate in God's creation and redemption of the world. For Lutherans, people who live out callings in service to others are what Luther termed "masks of God." They are worldly instruments of God's giving of life. When genetic technology upholds the dignity of the individual, it participates in God. When it respects the self-determination of the individual, it participates in God. When it meets the basic needs of all people, it participates in God. When it enables humans to flourish in times of environmental change, it participates in God. Such conditions for good and wholesome use of genetic engineering mirror Jesus' actions toward the weak, the sick, and the poor. They offer guidance for discerning whether and when humans may seek to enhance life through genetic engineering.

## **Key issues and moral disagreements**

Some thinkers see little moral significance in the distinction between therapy (or treatment) and enhancement. Some see no inherent difference between the enhancement of

life that humans have practiced for thousands of years in the development of tools and agriculture and the enhancement of the human body and mind through genetic technology. Others object that the integrity of the human genome should be respected and not altered. It is a gift from God. Humans should not “play God” in the sense of redesigning the basic genetic mechanisms of life. Consequently, the distinction between therapy and enhancement marks an important boundary in the proper use of human creativity.

In addition to the question of whether genetic enhancement as such is problematic, there are several questions about the proper use of this new power. First, there are issues of harm and risk of harm, and of consent to experimentation that need to be addressed. In 1978, when the first human being conceived through *in vitro* fertilization and embryo transfer was born, it was not known whether this technology could cause miscarriage or congenital damage. Louise Brown was born healthy, but she was not asked whether she wanted to participate in an experiment. Gene tinkering is complex and risky. People have died during gene therapy trials. Despite the amazing benefits that genetic enhancement could make possible, some people call for precaution, which does not necessarily mean that genetic research for human benefit should not be undertaken. But precaution requires rigorous care in avoiding risk, and people can disagree over safety standards and practices.

The question of harm comes into play in another respect when *in vitro* fertilization, preimplantation genetic diagnosis, and embryo transfer are used for genetic enhancement. The moral status of the embryo comes into play when multiple embryos are created and when some are destroyed as part of the process. People of faith disagree over the moral status of embryos and over the ethical treatment of embryos. Any comprehensive discussion of genetic enhancement needs to deal with this question.

The destruction of embryos is one consequence of genetic engineering research and one delivery system for germline manipulation. Critical observers take different sides on consequences on a larger societal level. First, because genetic science and technology require extensive societal resources, wealthy nations, and perhaps wealthy people in those societies, could be the first to have access to these new powers. This benefit would increase an existing social advantage, thus increasing the power gap between peoples. Some critics respond that the basic needs of all should be met first, before society devotes any resources to enhancement. Others say that new powers that benefit the rich will eventually benefit all. Genetics engineering presents a great question about the just use of limited societal resources for present and future generations.

Another issue of societal consequence concerns subtle changes in the values of society and the loss of social standing and freedom that may result from mass participation in genetic enhancement. While proponents of technological change often praise technology because it expands choices, others believe that great, new technology tends to become normative and socially transformative through unexpected consequences (i.e., e-mail). When preimplantation genetic screening becomes both diagnostically powerful and cheap, will it be normative such that people who choose not to use this technology will lose social respect or benefits? If preimplantation genetic screening becomes widely used, will most users choose to select out embryos with “disability”? Will people with disability be subject to new discrimination? Some thinkers argue that gene selection against disability will not result in loss of social standing for disabled people. Others worry that the societal gains of respect, equality, and inclusion of the 20<sup>th</sup> century will be eroded, if not lost.

Finally, concerning possible subtle social harms, genetic enhancement—be it life extension or children engineered for preferred traits—raises issues of the wisdom of pursuing enhancement when that pursuit involves significant expenditure of personal and societal resources at the expense of other life goods. Humans are creatures of desire. These desires are often frustrated. With genetic engineering, ancient human dreams of control over life seem within human grasp. While the pursuit of better life is laudable, humans need to reckon with limits to mastery over the world and to wrestle with contingency and finitude. They need to reckon with sometimes competing interests in freedom and self-determination. For proponents of genetic engineering, the orders of life are evolving, not static. Humans can and will grow into the new responsibility that they shoulder as a

result of dramatic interventions into life. Human striving to improve life does not undermine gratitude for the giftedness of life and for solidarity with those who suffer. Although “perfect” may be beyond human grasp, people need to pursue making life better because humans feel this calling to serve and because humans have, over the centuries, improved life on Earth. People of faith who hold this conviction believe that enhancing life through genetic intervention could be God’s will for us today.

## Invitation to conversation, prayer, and action



### QUESTIONS FOR DISCUSSION

- Is it helpful to distinguish between medical therapy and enhancement? If so, how does the distinction help us to weigh right and wrong, good and bad? How does it help us to understand the scope of human accountability? Are there limits to human genetic manipulation? Can genetic enhancement as such be understood as a new form of Christian love?
- Should Christians support life extension research and technology? If so, what kind of life span do we want? Consider a life where youth, adulthood, and aging are equally divided parts of life versus one where humans mature quickly, live a very long middle life and then age and die quickly. How will these decisions affect the needs of society and interactions between the generations? Suppose that genetic engineering could give Americans an average lifespan of 200 by 2050, how would society in 100 years be different?
- When people speak about a “duty,” they refer to an obligation. If it is permissible for Christians to use genetic technology to make humans better than well, is it a duty? Are we obligated to enhance our offspring? Do we owe it to future generations of humanity? Is there any sense in which Christians should affirm a “genetic duty”?
- Will genetic enhancement expand or erode choice and opportunity for future generations? Will new powers to diminish “disease” and “disability” undermine social respect and care for those who live with various diseases and disabilities? What societal risks must be addressed in order to pursue genetic enhancement responsibly?
- We live in a time when tens of millions of people in the United States and billions of people throughout the world lack resources to meet their basic healthcare needs. Is it justifiable to devote huge resources to enhancing life, especially when such expenditures will benefit future generations? Should genetic enhancement be an important part of the medical research agenda today? What reasons might justify the allocation of significant societal resources to future generations?

## Closing prayers

### INVITATION TO INTERCESSORY PRAYER

Pray for all who struggle to understand and struggle to implement the right use of genetic technology.

### PRAYING WITH THE TRADITION

Come, my Light, and illumine my darkness. Come, my Life, and revive me from death. Come, my Physician, and heal my wounds. Come, Flame of divine love, and burn up the thorns of my sins, kindling my heart with the flame of your love. Come, my King, sit upon the throne of my heart and reign there. For you alone are my King and my Lord. Amen.

(Prayer of Dimitri of Rostov, who lived 1651 to 1709)

## Resources

Ronald Cole-Turner, *The New Genesis: Theology and the Genetic Revolution* (Louisville: Westminster/John Knox Press, 1993).

Carl Elliott, *Better Than Well: American Medicine Meets the American Dream* (New York: W.W. Norton & Company, 2003).

Ramez Naam, *More Than Human: Embracing the Promise of Biological Enhancement* (New York: Broadway Books, 2005).

Bill McKibben, *Enough: Staying Human in an Engineered Age* (New York: Henry Holt and Company, 2003).

President's Council on Bioethics, *Beyond Therapy: Biotechnology and the Pursuit of Happiness* (Washington: U.S. Government Printing Office, 2003).

Michael J. Sandel, *The Case Against Perfection: Ethics in the Age of Genetic Engineering* (Cambridge: Harvard University Press, 2007).

## Endnotes

- 1 This story is also used in session A1.



# Response Form



# Response Form

## Genetics and Faith: Power, Choice, and Responsibility

Please return your response by November 1, 2009

Send to:

ELCA Task Force on Genetics, Church in Society  
8765 W. Higgins Rd  
Chicago, IL 60631

Or respond online at [www.elca.org/geneticsstudy](http://www.elca.org/geneticsstudy)

Or e-mail to: [Marilyn.Campbell@elca.org](mailto:Marilyn.Campbell@elca.org)

---

Please select the circle that indicates your response by filling it in completely.

1. Did you complete the study on your own or with others in a group?

on my own (Skip to question 2.)

in a group, but the answers on this questionnaire represent my opinions, not the groups

in a group, and this questionnaire represents the opinions of the group

1a. How many participants were in the group? (Feel free to estimate an average number.)

2 to 5

6 to 10

11 to 20

21 to 35

more than 35

1b. Who was the leader of the group?

a pastor

I'm not sure if the leader was a pastor or lay person

a lay person

2. How many people of the following characteristics were in the group, or which of the following describes you as an individual? If you are an individual, please put a "1" in the category that describes you. For a group, make your best estimate or ask people to raise their hands if possible. *Please enter only numbers and not percentages or "Xs."*

\_\_\_\_ 24 or younger

\_\_\_\_ female

\_\_\_\_ Asian or Pacific Islander

\_\_\_\_ 25 to 44

\_\_\_\_ male

\_\_\_\_ Black or African American

\_\_\_\_ 45 to 64

\_\_\_\_ Latino/Latina

\_\_\_\_ 65 or older

\_\_\_\_ American Indian or Alaska Native

\_\_\_\_ White or Caucasian

\_\_\_\_ Arab or Middle Eastern

3. Please indicate which sections of *Part A: A Framework for conversation, prayer, and action* you or the group read or discussed.

A1: The Global Reach of Genetics: Unprecedented powers and choices

A2: Caring for Neighbors: Vocation, responsibility and community

A3: Human Power Today: Innovation and accountability before God

A4: Christian Responsibility Today: Sources for guidance

A5: Toward a Lutheran Ethic in the Age of Genetics

4. Thinking back over those sections in *Part A* that you or the group read or discussed, what were the two or three points that produced the most significant discussion?

5 Still referring to *Part A*, what did you or the group think were the most important points that were made?

6. If your group discussed A5, which considers possible new elements for a social statement, please indicate which of the ideas you or your group found most valuable?

	Quite Useful	Useful	Unhelpful	Very Unhelpful	Not Sure
a. Respect and enhance the integrity of life before God	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. he precautionary principle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Long-term social and economic impact	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Encouraging scientific progress for the Common Good	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Christian <i>koinonia</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*(Please elaborate specific comments about any of these ideas in question 12 below)*

7. Again, referring to whatever sections of *Part A* were used, did you or the group think there were important points to be made that were **NOT** made?

8. Please indicate which sections of *Part B: Exploring responsibilities and engaging issues* you or the group read or discussed.

- B1: Genetics and Congregations: What should we do?
- B2: Genetics and Human Identity: Who are we, really?
- B3: Genetics and Social Location: How do things look from here?
- B4: Genetic Testing and Screening: What do we choose to know?
- B5: Genetic Engineering in Agriculture: How will we be fed?
- B6: Stem Cell Research and Therapy: What should we do?
- B7: Patenting Genes: Are they blessings or curses?
- B8: Enhancing Human Life: Would you like to be better than well?

9. Thinking back over those sections in *Part B* that you read and/or discussed, what were the two or three points that produced the most significant discussion?
  
  
  
  
  
  
  
  
  
  
10. Still referring to *Part B*, what did you or the group think were the most important points that were made?
  
  
  
  
  
  
  
  
  
  
11. Again, referring to *Part B*, did you or the group think there were important points to be made that were **not** made?
  
  
  
  
  
  
  
  
  
  
12. Please feel free to make any additional comments you believe would assist the work of the Task Force. Attach additional sheets if necessary.

Thank you for participating in the study! Return this response form by November 1, 2009.

Mail to: ELCA Study on Genetics and Faith, 8765 W. Higgins Rd, Chicago, IL 60631.

This form also is available online at [www.elca.org/geneticsstudy](http://www.elca.org/geneticsstudy)





# Appendices:

Leader's Guide

Genetics 101

Glossary



# Leader's Guide

This study may look as daunting as its subject matter. Imagine it, however, as a smorgasbord rather than as a long complicated scientific formula. It provides a variety of options for group use and individual reflection. It encourages selection according to the interests, time constraints, and situation of an individual or particular group and setting.

This point bears repeating: use as much or as little as makes sense given your particular circumstances. The study is designed to be accessible from different entry points, and each session is self-contained, although some cross references are provided. However much of the study is used, the one task we ask every user to complete, whether as individual or group, is to complete and return the response form on page 111!

## Preparing to lead the study

Below are answers to commonly asked questions that you might want to consider as you plan for the study and prepare to lead the sessions:

- 1. Who can lead this?** You can. Leaders do not need to be a pastor or a scientist! Discussion leaders from within the congregation can be recruited and prepared. If you have multiple leaders, consider working together through each session before the study sessions begin.
- 2. Who should participate?** Invite people of all ages—from youth to older adults—to participate. Though the study is not specifically geared to youth, high school youth may well have experiences that will add to the discussions, and they will certainly benefit from exposure to these pressing issues.
- 3. Which session shall we use?** Use whichever ones you think will provide the best engagement with the issues relevant to your group. Every group should plan on using the A1 as the introductory session, as well as session A5, which explores ethical issues that the task force has identified. Some groups will want to work systematically through the more general biblical, theological, and ethical material in the core of the study—the 5 sessions of Part A. Other groups will be most engaged by picking and choosing among topics of interest in Part B. It is quite possible to choose back and forth between Parts A and B as the group's interests develop. Most groups will want to use 5 to 8 sessions as the way to assure good exposure to the issues.
- 4. How long should a session take?** Sessions can be adapted for use in a variety of time frames, but it is probably best to plan one hour sessions, with fifteen minutes given to gathering the group, the brief opening, and the closing, and forty-five minutes given to review of the content and discussion. There will be more time for discussion if participants can read the session content before gathering for discernment.
- 5. How much background science is needed?** Discussing matters related to genetics can be considered scary because individuals often believe they “are not smart enough.” However, each session assumes a minimal background and provides explanation of key ideas. Leaders can help facilitate the discussion by doing some preparation work of their own. *Cracking the Code of Life*, the recommended DVD, can both help leaders to prepare and help to familiarize participants with the science and issues to be discussed. As a leader, take a moment to think about resource people in your area who might be asked to talk about specific genetics issues to your group. The glossary and a primer (see “Genetics 101”) are included for reference purposes, as well. Leaders will need to do some minimal preparation, but this will pay off as participants realize that understanding the basics of the science should not just be left to the “experts.”
- 6. Where can I get the DVD?** Segments of *Cracking the Code* can be downloaded at [www.pbs.org/wgbh/nova/genome/program.html](http://www.pbs.org/wgbh/nova/genome/program.html). The ELCA, however, is providing the DVD at no cost for those who would like a copy. It can be obtained either by calling the ELCA resources line at 800/638-3522 ext 2996 or by contacting Augsburg

Fortress, by phone or online. (800/328-4648 or [www.augsburgfortress.org](http://www.augsburgfortress.org)) If time is available, it will certainly help participants to view key segments of the DVD before beginning the study sessions or as part of each session. (Suggested segments of the DVD for each session will be found under the section called “Real life stories.”)

7. **What do I need to do in advance?** Read and become familiar with the content of the session you are leading. Watch the suggested segment from *Cracking the Code of Life*. Then decide which parts of the session you want to highlight and use. Lastly, identify the questions you will have the group focus on—you will not have time to use them all. Remember think of the study as a smorgasbord.
8. **Do we have to discuss all the questions?** No. The point, again, has been to provide a variety of questions that will allow the leader or group to tailor their discussion. Feel free to use just one question or to have break-out groups discuss different questions and summarize for the whole group just before closing.
9. **Who should do the Bible reading at the beginning?** It is best if someone besides the leader does it. Select a strong reader or readers to read aloud the scripture passage listed for that session. Either the leader or the reader can note the meditative aids in the adjoining sidebar before reading. Ask participants to close their eyes and just listen to the reading. This will allow them to hear things they may not otherwise. Do allow a brief time for silence following the reading. Then use the two simple questions in order to encourage participants to share an insight from what they have heard. If some time has lapsed and no one seems ready to share out loud, simply remind the group that God works through stillness too (Psalm 46:10), and then move on.
10. **What about the opening and closing?** Each opening could include a hymn (this should be chosen in advance, see page 119) and a prayer. Each closing includes suggested intercessory prayer related to the content of the session as well as a prayer taken from the broad Christian tradition. If you choose to follow the gathering space suggestion for the sessions (see “Gathering Time” below), you will need to prepare some items beforehand.

### Completing the Response Form

The task force is eager to receive responses to this study. Please record key insights and views as you participate in the study sessions or have someone do this informally for the group. The response form is found on page 119. Follow the directions for submitting it. It may be completed online at [www.elca.org/geneticsstudy](http://www.elca.org/geneticsstudy).

### Gathering time information

#### Preparation and space

Each gathering space is different, and you will want to be creative in how you arrange your space to accommodate your group’s needs. You are encouraged to incorporate the following elements to remind all of their baptism and to invite a focus on dwelling in the Word. Together they may provide a visual focus for the study sessions:

- A large bowl of water in a central location. If you are gathered around a table, it could be in the middle of the table; if using chairs in a room put it on a small table in the center or front of the room. You may want to find some blue cloth to cover the table; or “puddle” the cloth around the bottom of the bowl, allowing it to drape on to the table or cascade to the floor.
- A candle next to the bowl of water.
- A Bible, preferably large, open to the selected text of the day next to the candle.

As the study begins, you may wish to welcome the participants and orient them to the study, indicating that the study itself will be an experience of how we, as the baptized people of God, “dwell in the Scripture” as we engage in moral deliberation around issues

related to genetics. Invite them to note how the shape of the study itself begins with far more than a discussion of science and ethics. Rather, it invites us to open our minds and hearts to the hearing of the Word and to the discernment of what that Word means for our lives as baptized people of God in relation to these matters.

### ***Hymn suggestions***

#### ***Evangelical Lutheran Worship***

Hymn Numbers: 396, 513, 556, 574, 581, 597, 607, 610, 685, 708, 731, 732, 733, 736, 752, 787, 798, 879

#### ***Lutheran Book of Worship***

Hymn Numbers: 290, 294, 320, 343, 353, 360, 362, 364, 403, 406, 408, 423, 433, 463, 534, 558, 561

#### ***With One Voice***

Hymn Numbers: 684, 712, 752, 753, 765, 770, 771, 775, 779

#### ***This Far By Faith***

Hymn Numbers: 83, 130, 132, 192, 203, 222, 226, 230, 247, 283, 294

#### ***Worship & Praise***

Hymn Numbers: 14, 17, 22, 51, 69, 92, 98, 110, 114, 127, 137, 144, 147, 158

#### ***Libro de Liturgia y Cantico***

Borning Cry

Earth and All Stars

For the Beauty of the Earth

God, the Sculptor

Great is thy Faithfulness

Here I am Lord

Jesu, Jesu, Fill us With Your Love

Listen, God is Calling

Lord, Listen to Your Children Praying

Morning Has Broken

My Hope is Built on Nothing Less

On Eagle Wings

Santo es nuestro Dios (Holy is our God)

Sois la Semilla (You are the Seed)

Spirit of Gentleness

Take My Life That I May Be

The Summons

You Are Mine (I Will Come to You)

## Miscellaneous tips for leading the sessions

In addition to the preparation suggestions listed above, you may wish to keep in mind the following as you lead each session:

1. Following the selected scripture reading at the opening of the session, give the group time in silence to let the Word touch each individual, and to help them reflect on what they have heard. The comfort level of silence will likely grow as you practice it each week. Following the silence, you may ask the question provided: “What did you hear in this reading? Is there a word of God for us here?”
2. During “Discerning the Word,” encourage participants to keep their comments to one main insight in order to let everyone have a chance to speak. The material in the adjoining box is provided as meditation aids or conversation starters, but should not be used to preclude anyone’s contribution. The exercise is expected to take about 5-7 minutes, but as a leader you will need to determine the right balance between time for discernment, time for sharing insights, and the interest of getting to the chapter’s material.
3. It is most helpful if participants read the material for each session in advance. Nonetheless, it is possible and helpful for the leader to highlight key ideas of each session before getting to the discussion questions. At least one “Real Life Story” should be read (or watched) by all since they offer common ground and connections to everyday life.
4. If questions are raised about the meaning of terms or concepts in the study booklet that cannot be satisfactorily answered, record them and seek help in answering them before the next session.
5. In every group, some members are more vocal than others. Encourage broad participation whenever possible. Encourage everyone to discuss these important but complex issues in a spirit of mutual respect. Engaging in discussion of sensitive issues requires trust, and trust is built when participants listen respectfully to one another.



# Genetics 101: A brief reference for the science

## Introduction

Whether in this study, the daily headlines, or in the medical office, we encounter today many references to the science of genetics. Such repeated exposure doesn't mean that we understand this information. Much of it is so recent and the details so complex that many are tempted to give up trying to understand. Yet, a working familiarity with the science and technology is not simply a practical matter, but more importantly it is a moral one. Only a basic grasp will allow careful thinking and wise decision-making, whether for an individual or a society. This appendix is designed to give you easy access to the working knowledge necessary to participate in conversations about moral and theological choices presented in this study. It will not make anyone an expert! But it is hoped that it will be a useful reference for basic concepts like "gene" and "allele" and for understanding how we can manipulate them. Please note the online references scattered throughout that direct the reader to additional sources for understanding. The basic sources, however, include the following public domain sites:

[www.genome.gov](http://www.genome.gov)

[www.genetests.org](http://www.genetests.org) GeneTests: illustrated glossary

<http://ghr.nlm.nih.gov/> Genetics Home Reference: Handbook

## The Human Genome Project

Genetics refers to the study of biological heredity. However, genetics in its broadest sense serves as a catch phrase for the knowledge of how genes work, how we can use this information and the unprecedented challenges it poses. Much of the new appreciation for genetics has come from work on the Human Genome Project (HGP), a three billion dollar federally funded science project whose purpose is to sequence, map, and understand the human *genome*. The completion of the rough map of the human genome, announced on June 26, 2000, is widely regarded as a milestone that marks the transformation of the world of medicine. The HGP has revealed that there are probably about 20,500 human genes. The completed human sequence can now identify their locations. This ultimate product of the HGP has given the world a resource of detailed information about the structure, organization and function of the complete set of human genes. This information can be thought of as the basic set of inheritable "instructions" for the development and function of a human being.

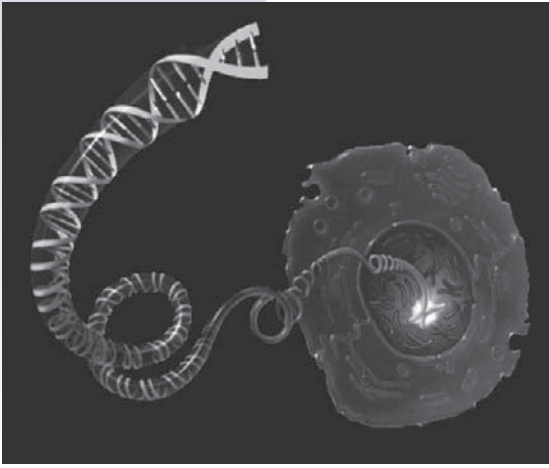
Upon publication of the majority of the genome in February 2001, Francis Collins, the director of National Human Genome Research Institute noted that the genome could be thought of in terms of a book with multiple uses: "It's a history book—a narrative of the journey of our species through time. It's a shop manual, with an incredibly detailed blueprint for building every human cell. And it's a transformative textbook of medicine, with insights that will give health care providers immense new powers to treat, prevent and cure disease." (For source and additional information see: [www.genome.gov/12011238](http://www.genome.gov/12011238).) Since February 2001, the work on the genome has shifted to understanding how the human genome functions in the role of creating gene products, most notably the many proteins for which genes code.

## Cells, DNA, and genes

Cells are the fundamental working units of every living system. All the instructions needed to direct their activities are contained within a DNA (deoxyribonucleic acid) sequence. The human genome (total composition of genetic material within a cell) is packaged into larger units known as chromosomes.

DNA is located inside each cell. It is coiled up inside the control tower of the cell, the nucleus. DNA is shaped as a twisted ladder, called a double helix.

The rungs of the ladder are composed of chemical unit pairs that match up. There are only 4 chemical units named by the first letter of the chemical names: A (adenine), T (thymine), C (cytosine), and G (Guanine). A always pairs on the ladder with a T and C pairs with G.

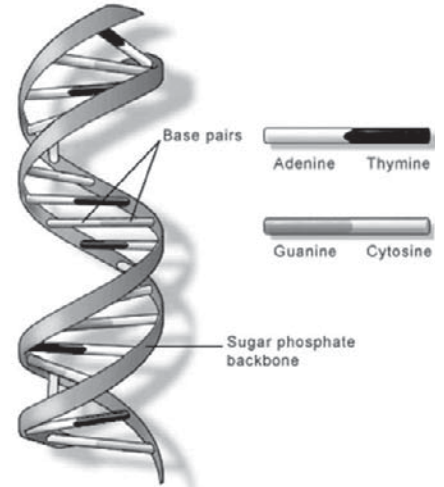


## Double Helix

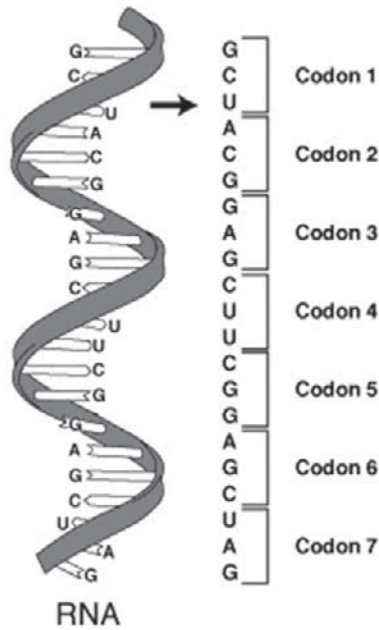
We might think of the “letters” as the language of genetic instruction. The letters define genes. All genes are made up of stretches of these four bases, arranged in different ways and in different lengths. Each gene has a unique DNA sequence. Genes comprise only about 29 percent of the human genome. The rest of the material making up chromosomes used to be called junk DNA. It is now suspected to consist of stretches of areas of base pairs not organized into genes whose functions may include providing chromosomal structural integrity and regulating where, when, and in what quantity proteins are made. The human genome is

estimated to contain 20,000-25,000 genes.

The novel aspect of this language is that all words are exactly three letters long and are without space between them. Each three-letter word, called a codon, is an instruction for one of the 20 amino acids that make up any given protein. Chemically, proteins are chains of amino acids linked together like beads on a necklace to form chains. In the human body there are only about 20 different amino acids, but they are linked in a huge assortment of arrangements that form many, many proteins. The order of the amino acids determines what protein is created and how it will function.



i. National Library of Medicine



RNA  
Ribonucleic acid

Courtesy National Human Genome Research Project

The protein building process then involves a series of messengers (RNA) which copy the code from the gene for the amino acids that are linked together to make proteins. These proteins then carry out their function either within the cell or by traveling to target cells elsewhere in the body. Protein functions range from creating ligaments, to carrying oxygen, to creating chemicals in the brain, to name a very few. Although genes get a lot of attention, it's the proteins that perform most life functions and even make up the majority of cellular structures. When genes are altered so that the encoded proteins are unable to carry out their normal functions, genetic disorders can result.

Proteins account, then for most of the remaining multitude of diverse tasks that structure and maintain the human body. There are many types of proteins. One example is hemoglobin, the protein in blood that carries oxygen. Each hemoglobin molecule is tremendously complex but its sole task is to carry a mere four oxygen molecules from the lungs to the rest of the body. Proteins include antibodies (the immune system's soldiers) and collagen, the protein that gives elastic strength to cartilage and ligaments. There are thousands of proteins. The important point is not the names but the recognition of the vast diversity and critical role that proteins play in our bodies.

Although science yet has much still to learn, current knowledge about genes is sufficient to permit us to test, engineer, and duplicate these fundamental instructions of life. It is the implications of these abilities that present the moral dilemma. Genes are not just instructions for proteins but also are “units of heredity”.

## Genes and chromosomes

The human genome is packaged into larger units known as chromosomes. They are physically separate molecules found inside the nucleus of the cell. Human cells contain two sets of chromosomes, one set inherited from each parent. Each cell, except sperm and eggs, contains 23 pairs of chromosomes which consist of 22 autosomes (numbered 1 through 22) and one pair of sex chromosomes

(XX or XY). Sperm and eggs contain half as much genetic material (in other words, only one copy of each chromosome).

Courtesy National Human Genome Research Project

Although each cell contains a full complement of DNA, cells use genes selectively. For example, the genes active in a liver cell differ from genes active in a brain cell since each cell performs different functions and therefore requires different proteins. Different genes can also be activated during development or in response to environmental stimuli such as an infection or stress.

## Genetics and health

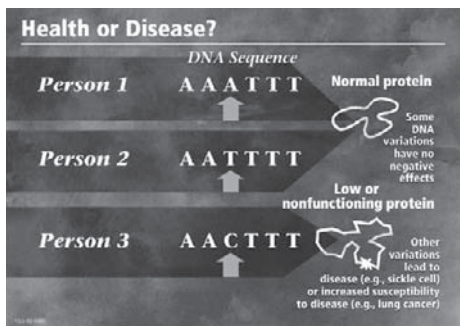
Genetic conditions can be categorized into three major groups: single-gene, chromosomal, and multifactorial conditions.

### Single gene disorders

Thousands of diseases are known to be caused by changes in the DNA sequence of single genes. A gene can be changed (mutated) in many ways, resulting in an altered protein product that is unable to perform its function. The most common gene mutation involves a change or “misspelling” in a single base in the DNA. Other mutations include the loss (deletion) or gain (duplication or insertion) of a single or multiple bases. The altered protein product may still retain some function but at a reduced capacity. In other cases, the protein may be totally disabled by the mutation or gain an entirely new but damaging function. The outcome of a particular mutation depends not only on how it alters a protein’s function but also on how vital that particular protein is to survival.

U.S. Department of Energy Genome Programs and the website <http://genomics.energy.gov>

### Chromosome disorders



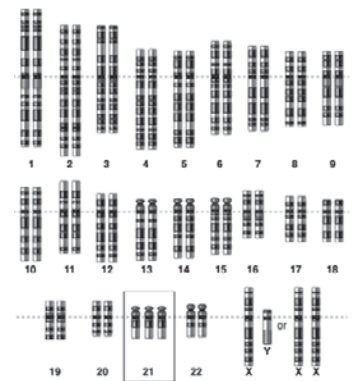
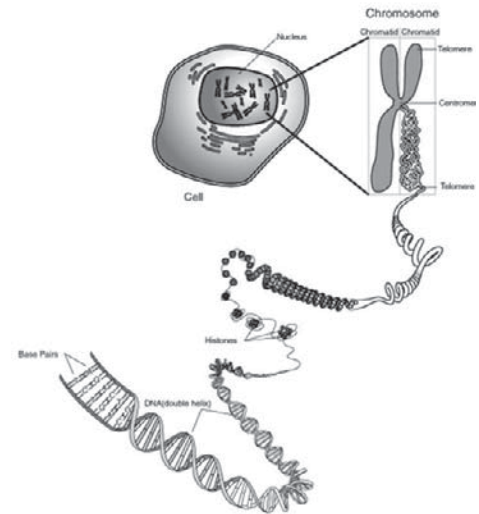
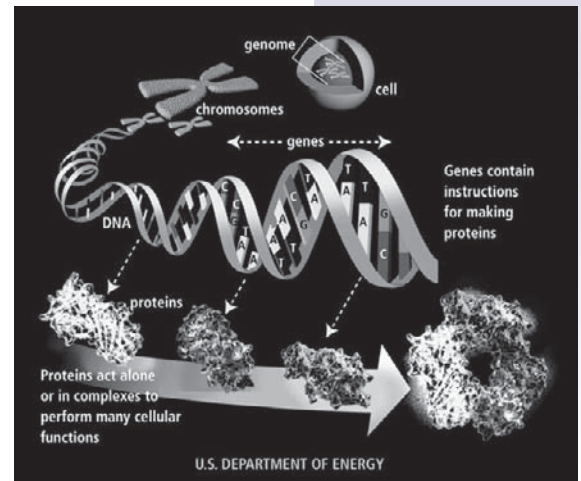
and often resemble one another even though they also resemble their families. Children and adults with Down syndrome have a wide variety of strengths and challenges. Cognitive ability necessitates special education in school and supervised living as adults.

Courtesy of the National Human Genome Research Institute

Chromosome disorders also include large or small rearrangements within or between chromosomes. These changes are called deletions, duplications, insertions, inversions, or translocations. These problems are due to segments of a chromosome that are lost, copied more than once, rotated end-to-end, or moved between chromosomes in the process of chromosomes copying themselves.

### Multifactorial conditions

Multifactorial inheritance means that many factors (multifactorial) are involved in causing a birth defect. The factors are usually both genetic and environmental, where a combination of genes from both parents, in addition to unknown environmental factors, produce the trait or condition. Often one gender (either males or females) is affected more frequently than the other

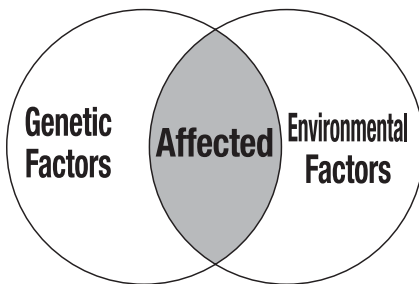


in multifactorial traits. There appears to be a different threshold of expression, which means that one gender is more likely to show the problem over the other gender. For example, hip dysplasia is nine times more common in females than males.

Multifactorial traits do recur in families, because they are partly caused by genes. The chance for a multifactorial trait or condition to happen again depends upon how closely the family member with the trait is related to you. For example, the risk is higher if your brother or sister has the trait or disease, than if your first cousin has the trait or disease. Family members share a certain percentage of genes in common, depending upon their relationship. Examples include height, neural tube defects such as spina bifida, heart disease, asthma and diabetes.

Multifactorial inheritance is actually the most common form of inheritance; most traits and characteristics are inherited in a multifactorial fashion. The expression of these traits and characteristics are always affected, in varying ways, by environmental factors as represented by this graphic.

### Identifying genetic conditions



Genetic tests can be used for many different purposes. The type of genetic testing that is done depends on the reason for the information.

**Newborn screening** is the most widespread use of genetic testing. [See Session B4 for more

information about newborn screening.] Almost every newborn in the U.S. is screened for several genetic diseases. Early detection of these diseases can lead to interventions to prevent the onset of symptoms or minimize disease severity.

**Carrier testing** can be used to help couples learn if they carry—and thus risk passing to their children—an allele for a recessive condition such as cystic fibrosis, sickle cell anemia, and Tay-Sachs disease. This type of testing is typically offered to individuals who have a family history of a genetic disorder and to people in ethnic groups with an increased risk of specific genetic conditions. If both parents are tested, the test can provide information about a couple's risk of having a child with a genetic condition.

**Prenatal diagnostic testing** is used to detect changes in a fetus's genes or chromosomes. This type of testing is offered to couples with an increased risk of having a baby with a genetic or chromosomal disorder. A tissue sample for testing can be obtained through amniocentesis or chorionic villus sampling. There is often confusion about screening during pregnancy and prenatal diagnosis during pregnancy.

Genetic tests may be used to confirm a **diagnosis** in a symptomatic individual or used to monitor **prognosis** of a disease or response to treatment.

**Predictive or predispositional/presymptomatic** genetic testing can identify individuals at risk of getting a disease prior to the onset of symptoms. These tests are particularly useful if an individual has a family history of a specific disease and an intervention is available to prevent the onset of disease or minimize disease severity. Predictive testing can identify mutations that increase a person's risk of developing disorders with a genetic basis, such as certain types of cancer.

### New ways to look at genetics using genomics

#### Human variation

The genetic sequences of different people are remarkably similar. When the chromosomes of two humans are compared, their DNA sequences can be identical for hundreds of bases. But at about one in every 1,200 bases, on average, the sequences will differ (Figure 1). One person might have an A at that location, while another person has a G, or a person might have extra bases at a given location or a missing segment of DNA. Each distinct "spelling" of a chromosomal region is called an allele, and a collection of alleles in a person's chromosomes is known as a genotype.

Differences in individual bases are by far the most common type of genetic variation. These genetic differences are known as single nucleotide polymorphisms, or SNPs (pronounced "snips"). By



identifying most of the approximately 10 million SNPs estimated to occur commonly in the human genome, the International HapMap Project ([www.hapmap.org](http://www.hapmap.org)) is identifying the basis for a large fraction of the genetic diversity or variation in the human species.

For geneticists, SNPs act as markers to locate genes in DNA sequences. Say that a spelling change in a gene increases the risk of suffering from high blood pressure, but researchers do not know where in our chromosomes that gene is located. They could compare the SNPs in people who have high blood pressure with the SNPs of people who do not. If a particular SNP is more common among people with hypertension, that SNP could be used as a pointer to locate and identify the gene involved in the disease.

Common diseases such as cancer, stroke, heart disease, diabetes, depression, and asthma usually result from the combined effects of a number of genetic variants and environmental factors. According to an idea known as the common disease-common variant hypothesis, the risk of contracting common diseases is influenced by genetic variants that are relatively common in populations. Not enough data are yet available to evaluate the generality of this hypothesis, but more and more widely distributed genetic variants associated with common diseases are being discovered, including variants that contribute to autoimmune diseases, schizophrenia, diabetes, asthma, stroke, and heart attacks. One of the many benefits of the International HapMap Project will be the use of the HapMap to learn more about the links between these common disorders and our genes.

### Ethical implications

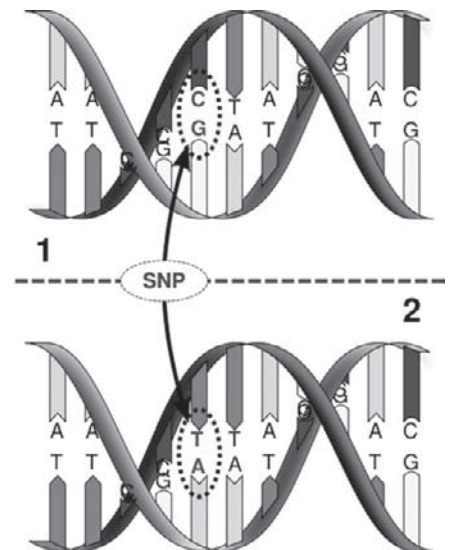
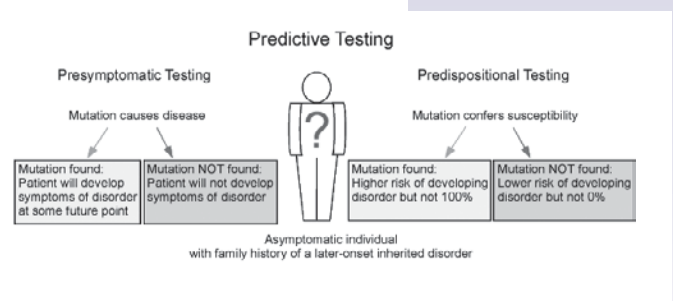
Knowledge derived from use of the HapMap also will result in advances that are difficult to predict today. Medical treatments could be customized, based on a patient's genetic makeup, to maximize effectiveness and minimize side effects. Genetic variants contributing to longevity or resistance to disease could be identified, leading to new therapies with widespread benefits. As with any new body of knowledge, the HapMap is likely to lead to both new challenges and to unexpected and unprecedented opportunities.

The individual DNA samples used in the Project are identified as coming from a male or a female, from one of the four populations participating in the study, and, in the case of the parent-child trios, from either one of the parents or the child. The samples are anonymous with regard to individual identity. Samples cannot be connected to individuals, and no personal information is linked to any sample. As an additional safeguard, more samples were collected from each population than were used, so no one knows whether any particular person's DNA is included in the study. No medical or phenotypic information was obtained from the donors.

Since the samples include no personal identifiers, the risk to individual donors that privacy might be compromised is minimal. However, because each sample is identified as coming from a particular population, group stigmatization and discrimination may occur from studies that use the HapMap. For example, researchers may find that a genetic variant associated with a higher-than-average risk of a disease is more common in one population than another. This information may be misinterpreted to mean that every member of a group has a higher-than-average risk of the disease, even though the higher risk may apply only to those individuals, inside the group or out, who have that variant.

Also, genetic findings could undermine established cultural or religious traditions or legal or political status. Many groups have firm beliefs about the origin of the group or about the relationship of the group to other groups, and these beliefs may be challenged by findings built on the use of the HapMap. In addition, genetic findings may conflict with the social and cultural methods that groups have developed to determine who is a member of that group.

Finally, the results of the Project could be misinterpreted to imply that constructs such as "race" are precise and highly meaningful biological categories. In fact, the information emerging from the Project is helping to demonstrate that common ideas about race emerge largely from social and cultural interactions and are only loosely connected to biological ancestry.



## Gene therapy

Although genes get a lot of attention, it's the proteins that perform most life functions and even make up the majority of cellular structures. When genes are altered so that the encoded proteins are unable to carry out their normal functions, genetic disorders can result. Gene therapy is a technique for correcting defective genes responsible for disease development. Researchers may use one of several approaches for correcting faulty genes:

- A normal gene may be inserted into a nonspecific location within the genome to replace a nonfunctional gene. This approach is most common.
- An abnormal gene could be swapped for a normal gene through homologous recombination.
- The abnormal gene could be repaired through selective reverse mutation, which returns the gene to its normal function.
- The regulation (the degree to which a gene is turned on or off) of a particular gene could be altered.

In most gene therapy studies, a “normal” gene is inserted into the genome to replace an “abnormal,” disease-causing gene. A carrier molecule called a vector must be used to deliver the therapeutic gene to the patient's target cells. Currently, the most common vector is a virus that has been genetically altered to carry normal human DNA. Viruses have evolved a way of encapsulating and delivering their genes to human cells in a pathogenic manner. Scientists have tried to take advantage of this capability and manipulate the virus genome to remove disease-causing genes and insert therapeutic genes.

Target cells such as the patient's liver or lung cells are infected with the viral vector. The vector then unloads its genetic material containing the therapeutic human gene into the target cell. The generation of a functional protein product from the therapeutic gene restores the target cell to a normal state. Gene Therapy holds tremendous promise for treatment, but has posed significant challenge because of the use of viral vectors to deliver the therapeutic gene. Unanticipated consequences have occurred in the context of clinical research such as leukemia in a child being treated for the disease made famous by David the bubble boy, severe combined immunodeficiency, SCID.

## Pharmacogenomics

Pharmacogenomics is the study of how an individual's genetic inheritance affects the body's response to drugs. The term comes from the words pharmacology and genomics and is thus the intersection of pharmaceuticals and genetics. It is hoped that this technology might one day enable drugs to be tailor-made for individuals and adapted to each person's own genetic makeup. Environment, diet, age, lifestyle, and state of health all can influence a person's response to medicines, but understanding an individual's genetic makeup is thought to be the key to creating personalized drugs with greater efficacy and safety. Pharmacogenomics combines traditional pharmaceutical sciences such as biochemistry with annotated knowledge of genes, proteins, and single nucleotide polymorphisms.

With this basic knowledge in hand, it should begin to be clear why our new knowledge about genetics is so significant. Genetic knowledge answers many questions about health and disease. Often, though, as information is gained, recognition of what we still need to learn becomes apparent. The knowledge we have now allows us to manipulate the genetic instructions upon which we all depend. This is awesome power.

## Patents

The patentability of inventions under U.S. law is determined by the Patent and Trademark Office (USPTO) in the Department of Commerce. A patent application is judged on four criteria. The invention must be “useful” in a practical sense (the inventor must identify some useful purpose for it), “novel” (i.e., not known or used before the filing), and “nonobvious” (i.e., not an improvement easily made by someone trained in the relevant area). The invention also must be described in sufficient detail to enable one skilled in the field to use it for the stated purpose (sometimes called the “enablement” criterion).



In general, raw products of nature are not patentable. DNA products usually become patentable when they have been isolated, purified, or modified to produce a unique form not found in nature.

In the United States, patent priority is based on the “first to invent” principle: whoever made the invention first (and can prove it) is awarded property rights for the 20-year period. Inventors have a one-year grace period to file after they publish. All other countries except the Philippines, however, follow a “first inventor to file” rule in establishing priority when granting patents.

As disease genes are found, complementary gene tests are developed to screen for the gene in humans who suspect they may be at risk for developing the disease. These tests are usually patented and licensed by the owners of the disease gene patent. Royalties are due the patent holder each time the tests are administered, and only licensed entities can conduct the tests.

## Cloning

The terms “recombinant DNA technology,” “DNA cloning,” “molecular cloning,” and “gene cloning” all refer to the same process: the transfer of a DNA fragment of interest from one organism to a self-replicating genetic element such as a bacterial plasmid. The DNA of interest can then be propagated in a foreign host cell. This technology has been around since the 1970s, and it has become a common practice in molecular biology labs today.

Reproductive cloning is a technology used to generate an animal that has the same nuclear DNA as another currently or previously existing animal. Dolly was created by reproductive cloning technology. In a process called “somatic cell nuclear transfer” (SCNT), scientists transfer genetic material from the nucleus of a donor adult cell to an egg whose nucleus, and thus its genetic material, has been removed. The reconstructed egg containing the DNA from a donor cell must be treated with chemicals or electric current in order to stimulate cell division. Once the cloned embryo reaches a suitable stage, it is transferred to the uterus of a female host where it continues to develop until birth.

Therapeutic cloning, also called “embryo cloning,” is the production of human embryos for use in research. The goal of this process is not to create cloned human beings, but rather to harvest stem cells that can be used to study human development and to treat disease. Stem cells are important to biomedical researchers because they can be used to generate virtually any type of specialized cell in the human body. Recent studies have transformed human skin cells into stem cells. This may offer an alternative to using embryo stem cells.

Reproductive cloning is expensive and highly inefficient. More than 90% of cloning attempts fail to produce viable offspring. More than 100 nuclear transfer procedures could be required to produce one viable clone. In addition to low success rates, cloned animals tend to have more compromised immune function and higher rates of infection, tumor growth, and other disorders. Japanese studies have shown that cloned mice live in poor health and die early.

Problems also may result from programming errors in the genetic material from a donor cell. When an embryo is created from the union of a sperm and an egg, the embryo receives copies of most genes from both parents. A process called “imprinting” chemically marks the DNA from the mother and father so that only one copy of a gene (either the maternal or paternal gene) is turned on. Defects in the genetic imprint of DNA from a single donor cell may lead to some of the developmental abnormalities of cloned embryos.

Due to the inefficiency of animal cloning (only about 1 or 2 viable offspring for every 100 experiments) and the lack of understanding about reproductive cloning, many scientists and physicians strongly believe that it would be unethical to attempt to clone humans. Not only do most attempts to clone mammals fail, about 30% of clones born alive are affected with “large-offspring syndrome” and other debilitating conditions. With so many unknowns concerning reproductive cloning, the attempt to clone humans at this time is considered potentially dangerous and ethically irresponsible.

## Genetically Modified (GM) foods

Although “biotechnology” and “genetic modification” commonly are used interchangeably, GM is a special set of technologies that alter the genetic makeup of such living organisms as animals, plants, or bacteria. Biotechnology, a more general term, refers to using living organisms or their components, such as enzymes, to make products that include wine, cheese, beer, and yogurt.

Combining genes from different organisms is known as recombinant DNA technology, and the resulting organism is said to be “genetically modified,” “genetically engineered,” or “transgenic.” GM products (current or in the pipeline) include medicines and vaccines, foods and food ingredients, feeds, and fibers.

Locating genes for important traits—such as those conferring insect resistance or desired nutrients—is one of the most limiting steps in the process. In 2006, a total of 252 million acres of transgenic crops were planted in 22 countries by 10.3 million farmers. The majority of these crops were herbicide- and insect-resistant soybeans, corn, cotton, canola, and alfalfa. Other crops grown commercially or field-tested are a sweet potato resistant to a virus that could decimate most of the African harvest, rice with increased iron and vitamins that may alleviate chronic malnutrition in Asian countries, and a variety of plants able to survive weather extremes.

On the horizon are bananas that produce human vaccines against infectious diseases such as hepatitis B; fish that mature more quickly; cows that are resistant to bovine spongiform encephalopathy (mad cow disease); fruit and nut trees that yield years earlier, and plants that produce new plastics with unique properties.

In 2006, countries that grew 97% of the global transgenic crops were the United States (53%), Argentina (17%), Brazil (11%), Canada (6%), India (4%), China (3%), Paraguay (2%) and South Africa (1%). Although growth is expected to plateau in industrialized countries, it is increasing in developing countries. The next decade will see exponential progress in GM product development as researchers gain increasing and unprecedented access to genomic resources that are applicable to organisms beyond the scope of individual projects.

Technologies for genetically modifying (GM) foods offer dramatic promise for meeting some areas of greatest challenge for the 21st century. Like all new technologies, they also pose some risks, both known and unknown. Controversies surrounding GM foods and crops commonly focus on human and environmental safety, labeling and consumer choice, intellectual property rights, ethics, food security, poverty reduction, and environmental conservation (“GM Foods: Benefits and Controversies” summary in appendix A).

### ***Genes and behavior (drawn from [genomics.energy.gov](http://genomics.energy.gov))***

No single gene determines a particular behavior. Behaviors are complex traits involving multiple genes that are affected by a variety of other factors. This fact often gets overlooked in media reports hyping scientific breakthroughs on gene function, and, unfortunately, this can be very misleading to the public.

Dubbing a gene as a “smart gene” gives the public a false impression of how much scientists really know about the genetics of a complex trait like intelligence. Once news of the “smart gene” reaches the public, suddenly there is talk about designer babies and the potential of genetically engineering embryos to have intelligence and other desirable traits, when in reality the path from genes to proteins to development of a particular trait is still a mystery.

With disorders, behaviors, or any physical trait, genes are just a part of the story, because a variety of genetic and environmental factors are involved in the development of any trait. Having a genetic variant doesn’t necessarily mean that a particular trait will develop. The presence of certain genetic factors can enhance or repress other genetic factors. Genes are turned on and off, and other factors may be keeping a gene from being turned “on.” In addition, the protein encoded by a gene can be modified in ways that can affect its ability to carry out its normal cellular function.

Genetic factors also can influence the role of certain environmental factors in the development of a particular trait. For example, a person may have a genetic variant that is known to increase his or her risk for developing emphysema from smoking, an environmental factor. If that person never smokes, then emphysema will not develop.

### **Human behavioral genetics**

Human behavioral genetics research seeks to understand both the genetic and environmental contributions to individual variations in human behavior. Research in this area is an intriguing but

extremely complex and challenging task, as indicated by the following points and example regarding intelligence:

- Behaviors, like all complex traits, involve *multiple genes*, a reality that complicates the search for genetic contributions.
- It often is difficult to *define* the behavior in question. Intelligence is a classic example. Is intelligence the ability to solve a certain type of problem? The ability to make one's way successfully in the world? The ability to score well on an IQ test? During the late summer of 1999, a Princeton molecular biologist published the results of impressive research in which he enhanced the ability of mice to learn by inserting a gene that codes for a protein in brain cells known to be associated with memory. Because the experimental animals performed better than controls on a series of traditional tests of learning, the press dubbed this gene "the smart gene" and the "IQ gene," as if improved memory were the central, or even sole, criterion for defining intelligence. In reality, there is no universal agreement on the definition of intelligence, even among those who study it for a living.
- Having established a definition for research purposes, the investigator still must measure the behavior with acceptable degrees of validity and reliability. That is especially difficult for basic personality traits such as shyness or assertiveness, which are the subject of much current research. Sometimes there is an interesting conflation of definition and measurement, as in the case of IQ tests, where the test score itself has come to define the trait it measures. This is a bit like using batting averages to define hitting prowess in baseball. A high average may indicate ability, but it does not define the essence of the trait.
- As with much other research in genetics, studies of genes and behavior require *analysis of families and populations* for comparison of those who have the trait in question with those who do not. The result often is a statement of "heritability," a statistical construct that estimates the amount of variation in a population that is attributable to genetic factors. The explanatory power of heritability figures is limited, however, applying only to the population studied and only to the environment in place at the time the study was conducted. If the population or the environment changes, the heritability most likely will change as well. Most important, heritability statements provide no basis for predictions about the expression of the trait in question in any given individual.

Much current research on genes and behavior engenders very strong feelings because of the potential social and political consequences of accepting the results. More than any other aspect of genetics, discoveries in behavioral genetics should not be viewed as irrefutable until there has been substantial scientific corroboration.



# Glossary

Adapted from:

[www.genome.gov](http://www.genome.gov)

[www.genetests.org](http://www.genetests.org) GeneTests: illustrated glossary

<http://ghr.nlm.nih.gov/> Genetics Home Reference: Handbook

**Acquired mutations:** gene changes that arise within individual cells and accumulate throughout a person's lifetime; also called somatic mutations. (See Hereditary mutation.)

**Alleles:** variant forms of the same gene. Different alleles produce variations in inherited characteristics such as eye color or blood type. In an individual, one form of the allele (the dominant one) may be expressed more than another form (the recessive one).

**Alzheimer's:** a disease that causes memory loss, personality changes, dementia, and ultimately, death. Not all cases are inherited, but genes have been found for familial forms of Alzheimer's disease.

**Amino acids:** A group of 20 different kinds of small molecules that link together in long chains to form proteins. Often referred to as the "building blocks" of proteins.

**Amniocentesis:** prenatal test where a needle is inserted into the womb and into the fluid in which the fetus floats. A few milliliters of fluid are withdrawn for testing.

**Anencephaly:** severe type of neural tube defect in which the top of the brain fails to develop.

**Autonomy** (as a moral category): the power of self-rule or direction; independence from outside guidance. An autonomous self is one that operates in an integrated, self-determining manner rather than according to outside authority or in response to outside stimuli. A dominant category of Enlightenment thinking. A key principle of medical ethics.

**Autosomal dominant:** One mutated copy of the gene in each cell is sufficient for a person to be affected by an autosomal dominant disorder. Each affected person usually has one affected parent. Autosomal dominant disorders tend to occur in every generation of an affected family.

In this example, a man with an autosomal dominant disorder has two affected children and two unaffected children.

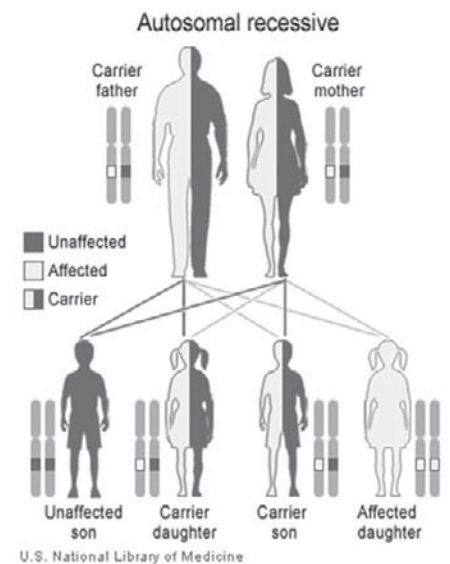
**Autosomal recessive:** Two mutated copies of the gene are present in each cell when a person has an autosomal recessive disorder. An affected person usually has unaffected parents who each carry a single copy of the mutated gene (and are referred to as carriers) (See illustration).

In this example, two unaffected parents each carry one copy of a gene mutation for an autosomal recessive disorder. They have one affected child and three unaffected children, two of which carry one copy of the gene mutation.

**Autosome:** any of the non-sex-determining chromosomes. Human cells have 22 pairs of autosomes.

**Base pairs:** the two complementary, nitrogen-rich molecules held together by weak chemical bonds. Two strands of DNA are held together in the shape of a double helix by the bonds between their base pairs. (See Chemical base.)

**Biosafety Protocol:** A treaty being negotiated under the Convention on Biological Diversity to set up a process for the safe movement across country boundaries of living genetically engineered organisms.



**Biotechnology:** Broadly defined, the use of biological processes of microbes and of plants or animal cells for the benefit of humans. When used in conjunction with genetic engineering, it is the genetic modification of an organism's DNA such that the transformed individuals have new traits that enhance survival or modify quality. The actual use of biotechnological methods began centuries ago, when plants and animals were selectively bred and microorganisms were used in the production of beer, wine, cheese, and bread. In addition to genetic engineering, biotechnology is concerned with such areas as plant tissue culture, gene splicing, enzyme systems, plant breeding, animal cell culture, immunology, molecular biology, and fermentation. Modern biotechnology is being used in medicine, fuel production, agriculture and food production, and criminal science, as well as in environmental activities.

**Bovine Somatotropin (BST/BGH):** Known both as BST and BGH (for bovine growth hormone), a naturally occurring protein that has been genetically engineered as a synthetic compound to stimulate milk production in cows.

**BRCA 1 and BRCA 2:** Autosomal dominant genes that normally code for a protein that restrains cell growth. Mutations in BRCA 1 and BRCA 2 are associated with Hereditary Breast and Ovarian Cancer.

**Carrier:** a person who has a gene mutation together with its normal allele. Usually refers to individual with one recessive allele and one fully functional allele.

**Carrier testing:** testing usually used to identify individuals who carry disease-causing recessive genes that could be inherited by their children. Carrier testing is designed for healthy people who have no symptoms of disease, but who are known to be at high risk because of family history.

**Cell:** a small, watery, membrane-bound compartment filled with chemicals; the basic subunit of any living thing.

**Chemical base:** an essential building block. DNA contains four complementary bases: adenine, which pairs with thymine, and cytosine, which pairs with guanine. In RNA, thymine is replaced by uracil.

**Chromosomes:** One of the threadlike "packages" of genes and other DNA in the nucleus of a cell. Different organisms have different numbers of chromosomes. Humans have 23 pairs of chromosomes, 46 in all: 44 autosomes and two sex chromosomes. Each parent contributes one chromosome to each pair, so children get half of their chromosomes from their mothers and half from their fathers.

**Clone:** a group of genetically identical genes, cells, or organisms derived, asexually, from a single ancestor.

**Cloning:** The process of making copies of a specific piece of DNA, usually a gene. When geneticists speak of cloning, they do not mean the process of making genetically identical copies of an entire organism.

**Codon:** Three bases in a DNA or RNA sequence which specify a single amino acid.

**Cystic fibrosis:** an autosomal recessive inherited condition in which a thick mucus clogs the lungs and blocks the ducts of the pancreas.

**Cytoplasm:** the cellular substance outside the nucleus in which the cell's organelles are suspended.

**Dementia:** severe impairment of mental functioning.

**DNA:** the substance of heredity; a large molecule that carries the genetic information that cells need to replicate and to produce proteins.

**DNA (Deoxyribonucleic Acid):** The molecule that encodes genetic information. It is constructed of a double helix held together by weak bonds between base pairs of four nucleotides adenine, guanine, cytosine, and thymine.



**DNA repair genes:** certain genes that are part of a DNA repair pathway; when altered, they permit mutations to pile up throughout the DNA. An example are the mismatch repair genes associated with hereditary colorectal cancer.

**DNA sequencing:** determining the exact order of the base pairs in a segment of DNA.

**Dominant allele (gene):** a gene that is expressed. Autosomal dominant disorders are produced by a single mutated dominant allele, even though its corresponding allele is normal. (See Recessive allele.)

**Down Syndrome:** also known as Trisomy 21 because of the presence of an extra chromosome 21. People with Down syndrome are often shorter than their family members and have mental retardation, upslanting eyes, and a broad short skull.

**Enzyme:** a protein that facilitates a specific chemical reaction.

**Eugenics:** literally it means “good genes” the term can indicate simply the study of hereditary improvement by genetic control. It usually, however, refers to any intentional strategy to direct human evolution through encouraging the transmission of “desired” traits while discouraging the “undesired” ones. Such strategy could include selective mating, prenatal testing, selective abortion, forced sterilization, ethnic cleansing or others.

**Expressivity:** the degree to which a gene produces an observable effect or characteristic.

**Gamete:** reproductive cell such as sperm or egg containing a half-copy of the genome.

**Gene:** a unit of inheritance; a working subunit of DNA. Genes are located on chromosomes. Humans carry approximately 25, 000 – 30,000 genes. Each gene codes for products important in cell functioning such as proteins and enzymes. Some genes code for a single product and some are known to code several products.

**Gene deletion:** the total loss or absence of a gene.

**Genetic engineering:** Very broadly, a technique used to alter or move genetic material (genes) of living cells. In the United States, under guidelines issued by Department of Agriculture’s Animal and Plant Health Inspection Service, genetic engineering is defined as the genetic modification of organisms by recombinant technology. Definitions used in Europe tend to be broader.

**Gene expression:** the process by which a gene’s coded information is translated into the structures present and operating in the cell (either proteins or others); the action whereby combinations of proteins produce an observable effect or function in a particular individual; the observable effect or characteristic in the individual due to the interaction of various proteins that determines how the individual organism will appear and function.

**Genetic linkage maps:** DNA maps that assign relative chromosomal locations to genetic landmarks. These could be either genes for known traits or distinctive sequences of DNA on the basis of how frequently they are inherited together. (See Physical maps.)

**Gene mapping:** determining the relative positions of genes on a chromosome and the distance between them.

**Gene stacking:** Combining traits (e.g., herbicide tolerance and insect resistance) in seed.

**Gene testing:** examining a sample of blood or other body fluid or tissue for biochemical, chromosomal, or genetic markers that indicate the presence or absence of genetic disease.

**Gene therapy:** treating disease by replacing, manipulating, or supplementing nonfunctional genes.

**Genetically Modified (GM):** An organism produced by genetic engineering techniques that allow the transfer of inherited characteristics from one organism to another, often between species. Bacteria, fungi, viruses, plants, insects, fish, and mammals are some examples of genetic material that have been artificially changed or altered in order to change some physical property or capability. Living modified organisms (LMOs), genetically engineered (GE) foods, and transgenic crops are other terms often used in place of GOs.

**Genetics:** the scientific study of heredity; how particular qualities or traits are transmitted from parents to offspring; The term often is used broadly to indicate the ethical, social, and legal questions that result from the knowledge of genetic science and its application.

**Genome:** the sum of the genetic material in the chromosomes of a particular organism.

**Genomic medicine:** use of information reflecting segments of the genome rather than individual genes in assigning risk for disease, response to treatment, or diagnosis.

**Genotype:** the actual gene carried by an individual (as distinct from phenotype that is the physical characteristics into which genes are translated).

**Germ cells:** the reproductive cells of the body, either egg or sperm cells.

**Germline mutation:** (See Hereditary mutation.)

**GMO:** GMO technically stands for Genetically Modified Organism and refers to any living form that has been modified by recombinant technology. However, the acronym GMO is sometimes loosely used, for instance to indicate plants and foods so modified.

**HapMap:** The HapMap is a catalog of common genetic variants that occur in human beings. Completing the HapMap constitutes the second phase of the Human Genome Project.

**Herbicide-tolerant Crops:** Crops developed to survive certain herbicides. These crops previously would have been destroyed along with targeted weeds, but now can be used by farmers as an effective weed control. The most common herbicide tolerant crops (cotton, corn, soybeans, and canola) are marketed under such names as Roundup® Ready (RR), resistant to glyphosate, a herbicide effective on many species of grasses, broadleaf weeds, and sedges; Liberty Link® (LL) corn, resistant to glufosinate-ammonium; and BXN cotton, resistant to bromoxynil.

**Hereditary mutation:** a gene change in the body's reproductive cells (egg or sperm) that becomes incorporated in the DNA of every cell in the body; also called germline mutation. (See Acquired mutations.)

**Human Genome Project:** an international research effort (led in the United States by the National Institutes of Health and the Department of Energy) to sequence the base pairs, identify the genes, and understand the human genome. It includes efforts to address the ethical, legal, and social issues that arise from this knowledge. (See Genome.)

**Huntington disease (HD):** an adult-onset disease characterized by progressive mental and physical deterioration; it is caused by an inherited dominant gene mutation that affects brain chemistry.

**Hurler or Hurler-Scheie syndrome:** an autosomal recessive disorder caused by inadequate production of an enzyme protein, characterized by facial and dental malformations, dwarfism, blindness from cataracts, and progressive dementia with symptoms beginning at a few months of age.

**Imprinting:** a biochemical phenomenon that determines, for certain genes, which one of the pair of alleles, the mother's or the father's, will be active in that individual.

**In vitro fertilization (IVF):** any of a number of methods of treating infertility by initially combining sperm and egg outside the body.

**Inborn errors of metabolism:** inherited diseases resulting from alterations in genes that code for enzymes.

**Karyotype:** The chromosomal complement of an individual, including the number of chromosomes and any abnormalities. The term is also used to refer to a photograph of an individual's chromosomes.

**Microarray technology:** A new way of studying how large numbers of genes interact with each other and how a cell's regulatory networks control vast batteries of genes simultaneously. The method uses a robot to precisely apply tiny droplets containing functional DNA to glass slides. Researchers then attach fluorescent labels to DNA from the cell they are studying. The labeled probes are allowed to bind to complementary DNA strands on the slides. The slides are put into a scanning microscope that can measure the brightness of each fluorescent dot; brightness reveals how much of a specific DNA fragment is present, an indicator of how active it is.

**Molecule:** a group of atoms arranged to interact in a particular way; one molecule of any substance is the smallest physical unit of that particular substance.

**Mutation:** A permanent structural alteration in DNA. In most cases, DNA changes either have no effect or cause harm, but occasionally a mutation can improve an organism's chance of surviving and passing the beneficial change on to its descendants.

**Neoplasm:** abnormal new growths, either malignant cancers or benign tumors.

**Newborn screening:** national programs that screen newborn infants to detect disease-related abnormalities or deficiencies which are associated with the development of impairment if intervention is not offered. Examples include deafness, or disease such as congenital hypothyroidism. Most disorders screened for are genetic conditions, but not all. Each state chooses the disorders included in screening.

**Norm (as a moral term):** a pattern, precept, or rule for decision and action. In this usage the term does not refer to what may be statistically standard or normal practice; it refers instead to a principle for regulating or judging conduct.

**Norm:** a typical, average, or standard characteristic or behavior.

**Nucleotide:** A subunit of DNA or RNA, consisting of one chemical base plus a phosphate molecule and a sugar molecule.

**Nucleus:** the cell structure that houses the chromosomes.

**Oncogenes:** genes that normally play a role in the growth of cells but when overexpressed or mutated, can foster the growth of cancer.

**Patent:** When applied to genetics, the government regulations or requirements conferring the right or title to an individual or organization to genes if there has been substantial human intervention.

**Penetrance:** a term indicating the likelihood that a given gene will actually result in disease.

**Pharmacogenetics:** the study of genetically-controlled variations in individual responses to drugs or products that use genetic susceptibility as part of the rationale for their use. Pharmacogenetics and pharmacogenomics are essentially the same process.

**Phenotype:** the observable characteristics of gene expression. (Compare with Genotype.)

**Physical maps:** DNA maps showing the location of identifiable landmarks, either genes or distinctive short sequences of DNA. The lowest resolution physical map shows the banding pattern on the 46 different chromosomes, while the highest resolution map depicts the complete nucleotide sequence of the chromosomes.

**Plant Breeding:** The technique of crossing plants to produce varieties with particular characteristics (traits) that are carried in their genes and passed on to future generations.

**Polymorphism:** A common variation in the sequence of DNA among individuals.

**Predictive/presymptomatic gene test:** a test to identify gene mutations that indicate whether an individual carries a genetic mutation associated with the development of a particular disorder. It predicts that the disorder associated with the genetic mutation is likely to occur.

**Preimplantation genetic diagnosis (PGD):** procedures that are performed on embryos prior to implantation, sometimes even on oocytes (egg cells) prior to fertilization in order to determine the presence of a specific genetic sequence associated with a disorder. PGD is considered an alternative to prenatal diagnosis.

**Preimplantation genetic screening:** procedures that do not look for a specific disease but use PGD techniques to identify embryos at risk.

**Prenatal diagnosis:** examining fetal cells taken from the amniotic fluid, the primitive placenta (chorion) for biochemical, chromosomal, or gene alterations in order to provide a specific diagnosis of a fetus during the pregnancy.

**Protein:** a large, complex molecule composed of amino acids. The sequence of the amino acids is determined by the sequence of the base pairs in the gene that encodes it. Proteins are essential to the structure, function, and regulation of the body. Examples are hormones, enzymes, and antibodies. Proteins have a three-dimensional structure that is vital for their action within cells and between cells.

**Recessive allele (gene):** Autosomal recessive genes refers to gene expression that is revealed when the dominant form of the gene is not present. Usually recessive genes result in absent or diminished and protein products. Recessive genes are not always associated with disease. Autosomal recessive disorders develop in persons who receive two copies of a gene, each with mutations leading to the absence or low functioning of a gene product. (See Dominant allele.)

**Reproductive cells:** egg and sperm cells. Each mature reproductive cell carries a single set of 23 chromosomes.

**Restriction enzymes:** enzymes that can cut strands of DNA at specific base sequences.

**RNA:** a chemical similar to DNA. The several classes of RNA molecules play important roles in protein synthesis and other cell activities. Messenger RNA or mRNA is the template for protein synthesis. Each set of codons specifies a certain protein in the sequence of amino acids that comprise the protein. The sequence of a strand of mRNA is based on the sequence of a complementary strand of DNA.

**Screening:** a medical test used to identify individuals in a population who may have an important health risk. The findings of screening tests often include false positives and false negatives, but the purpose of screening is to identify those individuals who should go on for more definitive diagnostic testing.

**Sex chromosomes:** the chromosomes that determine the sex of an organism. Human females have two X chromosomes; males have one X and one Y.

**Sickle cell anemia:** an inherited, potentially lethal disease in which a defect in hemoglobin in the blood causes red blood cells to lose their disc shape. The sickle shaped cells and loss of blood cells leads to damage to organs throughout the body.

**SNPS (single nucleotide polymorphism):** Common, but minute, variations that occur in human DNA at a frequency of one every 1,000 bases. These variations can be used to track inheritance in families. SNP is pronounced “snip”.

**Somatic cells:** all body cells except the reproductive cells, egg cells, and sperm cells.

**Somatic mutations:** (See Acquired mutations.)

**Tay-Sachs disease:** an inherited disease of infancy characterized by profound mental retardation and early death; it is caused by a recessive gene mutation.

**Transcription:** the process of copying information from DNA into new strands of messenger RNA (mRNA). The mRNA then carries this information to the cytoplasm, where it serves as the blueprint for the manufacture of a specific protein.

**Translation:** the process of turning instructions from mRNA, base by base, into chains of amino acids that then fold into proteins. This process takes place in the cytoplasm, on structures called ribosomes.

**Translocation:** a relocation of genetic material between chromosomes or from one chromosome to another. The swapping can involve large segments of chromosomes with many genes or tiny fragments of a chromosome with few genes. Translocations can be balanced, in which case, there may not be any visible consequences or can be unbalanced, which may lead to birth defects and/or miscarriages.

**Trisomy:** three copies of a chromosome instead of the usual two. The most common example is Down syndrome, trisomy 21. Other chromosome trisomies include trisomy 13 and trisomy 18 or an extra X or Y chromosome.

**X-linked dominant:** describes a dominant trait or disorder caused by a mutation in a gene on the X chromosome.

**X-linked lethal:** A disorder caused by a dominant mutation in a gene on the X chromosome that is observed almost exclusively in females because it is almost always lethal in males who inherit the gene mutation.

**X-linked recessive:** A mode of inheritance in which a mutation in a gene on the X chromosome causes the phenotype to be expressed in males who have only one X chromosome and in females who have a copy of the gene mutation on each of their two X chromosomes.











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