

Genetics! Where Do We Stand as Christians?

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Preface

Genetics! Where Do We Stand As Christians? The exclamation point and the question mark in the title alert readers that this study explores new and challenging developments. Our society is in the process of trying to understand what the rapidly expanding knowledge about human genes means and to discern what we should do about it. Because we have the scientific and technological ability to do something does not mean we should do it—or should not do it. Christians in company with others need to appraise this new knowledge and power to manipulate genes in light of who we are, what we believe, and what we hold to be good and right.

This study prepares Christians to take on this task in an informed and faithful way. It provides reliable knowledge about genetics, highlights areas of impact and controversy, draws upon the Christian tradition for its perspective, clears away mistaken alternatives, and presents options we face. It helps readers take a stand on genetics as Christians.

Genetics! Where Do We Stand As Christians? is meant to encourage learning and moral discourse among members in our church as well as in other church bodies. It is intended for use in congregational forums and other settings where Christians explore the relationship of their faith to everyday life. It also may be used profitably as a resource for individual study. It is not a church policy statement on genetics. The study expresses the commitment of the Evangelical Lutheran Church in America (ELCA) to promote "open-ended deliberation on specific contemporary social concerns without the pressure of legislative decision or community consensus." (See "Policies and Procedures of the Evangelical Lutheran Church in America for Addressing Social Concerns," 1997).

This study follows upon and draws considerably upon a book on genetics authorized by the board of the ELCA's Division for Church in Society (DCS). Readers are encouraged to consult that book, Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science, edited by Roger A. Willer (Minneapolis: Kirk House, 1998), for more extensive treatment of many of the issues in this study. Readers may also want to consult another related study produced by DCS: Human Cloning: Papers from a Church Consultation (2001), also edited by Willer. Ordering information on these two resources may be found on page 67.

Rev. Willer brings his experience with these two projects to author this study. Willer, a member of Reformation Lutheran Church in Eastlake, Ohio, has served as an Associate of Studies in the ELCA's Division for Church in Society during the production of this study. He is a doctoral candidate in theology at the University of Chicago. DCS thanks Mark Buckheim, Robert R. Lebel, Scott Nichols, Laurie Ryan, Charles Smith, and Deon Stuthman, who read and commented on drafts of this study. The Division is also grateful to the following congregations and their leaders who tested this material in discussion forums: John Haselow and Hope Lutheran, Cleveland Heights, Ohio; Jim Hildreth and St. Paul Lutheran, Villa Park, Illinois; Debra Johnson and Good Shepherd Lutheran, Alexandria, Virginia; Steve Shrider and Zion Lutheran Church, Clarence, New York; and Charles Smith and Trinity Lutheran, Newport News, Virginia. The generous efforts of these people have significantly strengthened the final product.



User's Introduction

"Genetics" is hard to miss in the United States today. News about it appears regularly, sometimes daily, in headlines announcing scientific breakthroughs, new applications, and the related moral questions. Genetic knowledge can lead to amazing medical therapy, allow informed choices, set free the wrongly accused, dramatically improve crop yields, and spin off whole new industries that respond to the ailments and misfortunes of life. Many commentators talk about the Twenty-First century as the age of biological control because this new knowledge is granting human beings the power to change, at the most fundamental levels, what humans are and what they are going to be.

But the fast pace of these changes may remind us of an old story: An airplane captain's voice speaks calmly over the intercom, "Good afternoon ladies and gentlemen, our flight today is going well, with one minor detail. The good news is that the engines are working well, we have minimal turbulence, and we are making great time. The hitch is that we are lost in the clouds and our radar has quite working."

While we may celebrate the potential of genetic knowledge, its application presents challenges that range from interesting questions to troubling personal crises and social dilemmas. It is true, as Ecclesiastics 1:18 reminds us, "Those who increase knowledge increase sorrow." Often these challenges seem to outstrip the social and moral radar that helps us to determine a safe and appropriate course. How then shall we live in this increasingly genetized society? What perspective should our faith lead us to on these developments? What do we think God's intentions are in all of this? What should the church, and we as members of it, be saying in the public debates that ensue? Where do we stand as Christians?

The Christian tradition does not have ready-made solutions to these questions. It does have a treasury of resources to help Christians think through the challenges. This guide has been written to help make those resources readily accessible to pastors and lay people. It is designed to provide a working knowledge of the many faces of "genetics" and to aid Christians in determining where they should stand on the issues. It does not attempt to provide "all the answers," but it does attempt to help the reader tune up his or her radar.

About this Guide

Content

Putting one's radar to work involves attention to four kinds of material. First, this guide attempts to help each reader become aware of the *pre-understandings* (pre-understandings are explained below) that he or she brings to this search for knowledge and understanding. Second, there is a constant emphasis on *learning the basics* of the science, medicine, economics, and so forth. To tune up a radar, one must know the facts. All facts, however, must be interpreted, and this, for a person of faith, involves attention to the third kind of material, *theological analysis and reflections*. Finally, the challenges raised by genetics require *decision*, whether on a personal or social level. This guide concludes each chapter with exercises that encourage the use of one's moral imagination to arrive at concrete moral conclusions, tentative and incomplete as they will be. Suggestions are also included for possible forms of action.

Audience

The guide is designed for use in adult study groups, but also doubles as an entry point for the individual reader. The first two chapters, therefore, provide a foundation in scientific concepts and theological ideas. Each additional chapter takes up one of the many topics that result from our new knowledge of genetics. This topical arrangement permits individuals or groups to focus on those aspects of genetics that are of most concern to them. Each section also provides references to other books and materials, primarily faith-based ones, that would allow the reader to delve more deeply into the subject.



This guide is written with Christians of the Lutheran tradition in mind. The bulk of the materials upon which the guide depends are taken from within that tradition. This follows from the guide's intention to make readily accessible to pastors and lay people what specialists within the Evangelical Lutheran Church in America (ELCA) are saying about these matters. It is, however, hoped that non Lutherans also will find the guide relevant and beneficial. It is recognized that attention limited to Lutheran sources represents an inevitable loss since nearly every major church body now has some resources on genetic questions. These include denominational reports or social statements as well as fine books and articles by thinkers within these traditions. This guide does refer readers to several of these resources in its bibliographic sections and non Lutheran readers can trace connections to resources within their tradition from the books on the bibliography.

Additional Chapters

Since genetics moves so rapidly, it is a constant challenge to provide up-to-date information and reflection. This guide is fully aware that many important topics are missing. Some of those topics will be addressed in additional chapters that will be made available online. Chapter eight, for instance, will look at the implications and issues of adult genetic testing and screening. This use of the Web to provide additional chapters that continue the work of this study will also provide one means for addressing new developments. Readers are encouraged to visit the ELCA Web site for this purpose. (See page 66 for further information.)

About Each Section

After the two initial chapters, a regular pattern of section headings becomes evident in the topical chapters. These chapters are designed to be semi-independent, but the patterns of each section provides continuity in the overall effort to inform readers and to encourage discernment. The following descriptions may provide a helpful reference to the rationale behind this approach. Leaders of study groups may especially find this background helpful.

Introduction

The initial material in each chapter—it might be called a *contact point*—provides a way to establish connection with the genuine challenges and issues of that topic. This is how moral and theological thinking works—an event in life disrupts normal thought patterns or requires decision. Questions, a search for information, and reflection follow. The section entitled *Introduction* helps to sketch out the relevant issues, suggest the themes, and focus the questions that form the threads weaving together that chapter.

Personal Experience and Values

This guide is conceived as an exercise in "faith seeking understanding," a venerable theme of the Christian tradition. Implied in that theme is the assertion that all efforts to understand something new involves some *pre-understandings*. Pre-understandings are the broad and pervasive sets of belief, knowledge, experiences, commitments, emotions, and judgments that every individual brings to any new topic. There is no neutral approach to any information. Pre-understandings are the inevitable filters used by each person to seek out new knowledge or understanding. This section of the chapter, then, identifies several relevant questions that can help the reader get in touch with some of the pre-understandings he or she brings to the topic. It is hoped that readers will take the time to allow these questions to help surface his or her experiences, values, and assumptions. This will foster openness and insight.

Gathering Input

This section begins with information from science, economics, or other relevant disciplines and then considers theological themes. These two sets of material provide the basic ingredients for reflection on each topic.

Deliberation

Reflection and discussion at some point must be put to the test. This section is designed to encourage readers to put the ideas of the chapter to work in moral *deliberation* (deliberation as used in this guide indicates thinking oriented toward moral decision or action). It offers a specific exercise that encourages the reader to use his or her moral imagination. That is, the reader is invited to imagine what she or he would think or do in the given situation, based on what they know and understand at that point in time.



The point is to focus his or her present knowledge and understanding on a specific question. The result, admittedly, will be tentative and incomplete. Nonetheless, the application of theoretical ideas to a practical instance of deliberation involves the reader in a crucial exercise of learning.

Taking the Conversation With You

The activities suggested in this section are not intended to take the place of questions or discussion within the chapter. They are provided, however, in order to encourage participants to apply or act upon what they have learned. The ultimate goal of a study is not knowledge alone, but transformative action. Individuals and groups might use one of the suggestions, or come up with their own, in order to develop a hands-on project growing out of their discussions.

For Further Investigation

The final section of each chapter provides a short list of books or Web sites that represent more in-depth resources. These references are far from comprehensive, but they represent some helpful and accessible materials for further investigation. It is worth noting that the *Selected Bibliography* at the end of this guide lists additional resources of a more general nature.



Leader's Guide

As a leader, you play a critical role in this study even though the exact role will depend on the nature of the group and how this study is used. You are responsible to make sure resources are available for each session and to guide the discussion of the material. Groups also need a leader to encourage everyone's participation, summarize learning, and help coordinate any possible actions that may arise from your study. You do not need to be a scientist, or theologian, or a professional of any kind to lead this study—but careful preparation and extra study will pay dividends for the group you are leading.

In addition to reading this guide in advance, group leaders are encouraged to read a brief ELCA document entitled *Talking Together as Christians about Tough Social Issues*. (Information for ordering this document may be found on page 67.). Attention to its guidance for faith-based discussion of controversial topics can help steer your group toward thoughtful discussions that generate more "light than heat." Its insights in group discussion dynamics can be valuable, as well, for the many issues in genetics that are not controversial.

Session Planning

Choose which Chapters to Study

A group's first step is to choose which chapters to use and how to use them. (The group may adjust their decisions later, of course.)

This guide is written to permit maximum flexibility and selectivity. The first two chapters are foundational, while the rest are topical and semi-independent of each other. This means that groups should plan to begin with the first two chapters, but may select among the others without disruption to the educational flow. This feature will hold for additional chapters made available online at the ELCA Website [see page 66 for further information]

Choose How to Use the Chapters

This guide is designed to permit different study groups to approach the material at a level they find appropriate.

Groups may use the study as an introductory survey in the educational setting common to many congregations: A forty-five minute, roughly, Sunday morning adult class in which participants have taken little time to prepare. This approach covers one chapter per session, but requires the leader to be thoroughly prepared to introduce and highlight key ideas and guide discussion accordingly.

Classes or study groups, alternatively, can engage the material at a deeper level by spending two sessions on each chapter. This goal may be accomplished in at least two ways:

- 1) Ask participants to read through the entire session's material ahead of class. (Most readers have found that the chapters require about twenty to thirty minutes to read.) Suggest that they mark or record those questions, insights, and ideas that they find most important. Encourage participants to share these as the class moves through each section.
- 2) Ask participants to come to class prepared to read through the material together and reflect upon it as they go. This will require the leader to prepare ahead of time for using the built-in discussion points (such as *Personal Experience and Values* and *Deliberation*) of each chapter.

Preparation

Be sure each participant has a copy of this guide or of the relevant chapter. Make these available before your first session and encourage all participants to read the short *User's Guide* which introduces the study and explains how it is designed.



If desired, a leader might spread responsibilities among class members by:

- 1) Assigning one person to lead opening and closing prayers or devotions.
- 2) Assigning leadership of one session to an individual or a small group. Encourage these participants to become as familiar as possible with their material. Suggest the preparation of questions or discoveries taken from their advance reading. Suggest how they might sharpen their preparation by using the resources mentioned at the end of *For Further Investigation* or by interviewing people in the congregation on the ethical issues raised in the session.
- 3) Inviting the pastor or other appropriate specialists who could enrich discussion of a specific topic.

Goals

The goal of your work as a leader should be threefold:

- To help participants gain a working knowledge of the science, theology, and other information involved.
- To help participants gain their own understanding of the various benefits, questions, challenges, and burdens that come with genetic knowledge.
- To help participants to be able to apply a Christian perspective on the moral and social decisions that are, or must be made, regarding the use of genetic knowledge.

Doing a Session

Begin with Prayer

Engage

Highlight or read sections of the session one at a time. A leader might ask those who have read ahead of time to summarize the material and supply whatever background they have been able to discover. Encourage questions or comments from participants as you read. Do encourage participants to share appropriate personal stories raised by these reflections, especially when using the section entitled *Personal Experience* and *Values*.

Reflect

Reflection should occur as your group works through each section, especially the one entitled *Gathering Input*. You many want to encourage this reflection by developing brief questions for use along the way. Generally, participants will also raise questions as they seek clarification and gather input.

Deliberate

Use the suggested exercise, involving a specific case or set of recommendations, as a way to encourage participants to make choices, tentative and incomplete as they may be. Be sure that participants understand the tentative nature of this exercise, but encourage them to use his or her moral imagination to move beyond general discussion to the hard work of deciding.

Apply

Briefly encourage participants to do some of the suggested activities in the section entitled *Taking the Conversation With You* during the week. Do so by beginning each session with a time in which they can share their experience and insight from doing the activities. If the group has chosen a group project, each session could begin with reports about this activity.

Evaluate

After your discussion, near the end of each chapter's conclusion, be sure to think through together the implications of what you have learned for the life of your congregation.

Close with Prayer or Devotions



Chapter One—A Primer in Genetics

Introduction

"Genetics" is hard to miss in the United States today. Whether sometimes in the daily headlines or in a medical office, or in the decisions that a loved one has to make, we encounter genetics repeatedly. This familiarity, however, does not mean that the science behind it is well understood. The knowledge is so recent and the details so complex that many are tempted to give up on it. This is unfortunate because a working knowledge of the science behind the social challenges is within anyone's reach. Further, this working grasp of the science and technology is not only a practical matter, but, more importantly, a moral one. Only this basic grasp will empower careful thinking and wise decision-making, whether for an individual or a society. This chapter then is designed to give the reader the working knowledge necessary to participate in conversations about the promises and the perils our culture faces in this age of biological control. Be patient as you read through this material. Such effort will pay dividends in getting a handle on the strange language of genetics. The task of this chapter will be achieved when the reader has a working grasp of the concepts of gene, allele, and the Human Genome Project, as well as a general understanding of how we can manipulate genes and make use of genetic knowledge.

What questions do you bring to this topic? As we seek either factual explanation or meaningful understanding, we learn by posing questions and answering them. Often these questions are only vaguely present in one's mental background, but they are there. Therefore, it helps greatly to identify some of these questions before beginning to read or discuss. Take a moment to identify two or three questions that you bring to the topic of genetics. In a group study, it is helpful to allow each person to share one of his or her questions. In a large group, or one with new participants, this can be the occasion to briefly introduce oneself.

Genetics 101

Genetics in its narrowest sense simply refers to the study of biological heredity and how genes effect the functioning and features of a living body. Genetics in its broadest sense serves as a catch phrase for the knowledge of how genes work, the impressive abilities it gives us, and the unprecedented challenges it poses. (This guide generally intends this second and broader meaning, except at certain places in this first chapter.) The center of this accumulating knowledge is the Human Genome Project (HGP), a three-billion-dollar federally funded science project whose purpose is to sequence, map, and understand the human genome. (A genome is the entire set of genes in any living creature.) The completion of the rough map of the human genome was announced on June 26, 2000, and is widely regarded as a milestone that marks the transforma-

tion of the world of medicine. Just as dramatically, genetics will revolutionize a range of human endeavors—from bearing children to farming to how we understand what it means to be a human being. The reason genetics impacts human society so dramatically becomes clear when one understands what a gene is and how it works.

So what is a *gene?* Simply stated, a gene is a piece of chemical material (the chemical's name is Deoxyribonucleic acid—DNA) that serves as: 1) the source of the instructions that build and maintain living bodies; and 2) the unit that passes along such information to succeeding generations. The promise and peril of genetics lie in the fact that we are dealing with these fundamental units, this foundation of present and future life. We will now examine each function of the gene as the route to a working knowledge of genetic science.



Genes: Instructions for Proteins

The nutrition label on packaged foods identifies carbohydrates, fats, and proteins as the main components of food. For our purposes, human bodies can also be divided into these categories. Carbohydrates function primarily as the body's energy source while fats are primarily the body's way to store excess energy. Proteins account for most of the remaining multitude of diverse tasks that structure and maintain the human body.

There are many types of proteins. Hemoglobin (the protein in blood that carries oxygen) is one example. Each hemoglobin molecule is tremendously complex, but its primary task is to carry a mere four oxygen molecules from the lungs to the rest of the body. Other well known proteins include antibodies, the immune system's soldiers. Another is collagen, the protein that gives elastic strength to cartilage and ligaments. Yet other proteins, called

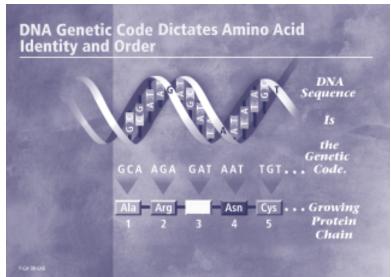
enzymes, act as catalysts in the thousands of biochemical pathways that give cells their function. The important point is not the names, but the recognition of the vast diversity and critical role that proteins play in our bodies.

The U.S. Human Genome Project (in conjunction with a worldwide effort) began in 1990 as a 15-year effort coordinated by the U.S. Department of Energy and the National Institutes of Health.

Project goals are to:

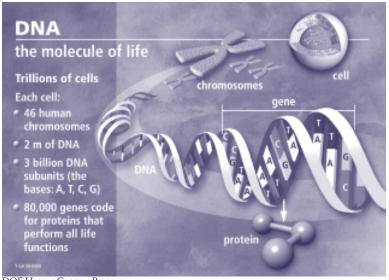
- identify all the approximately 50,000 genes in human DNA,
- determine the sequence of the three billion chemical base pairs that make up human DNA,
- · store this information in databases,
- · develop tools for data analysis,
- transfer related technologies to the private sector, and
- address the ethical, legal, and social issues (ELSI) that may arise from the project.¹

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 colored beads—that is, amino acids—but they are linked in a huge assortment of arrangements that form the multitude of proteins. These necklaces range from only a few to several thousand beads long. The order in which these beads are arranged (called the sequence) determines what protein is created and how it will function. The instructions for making these amino acids and their proper sequence are encoded in genes (refer to graphic). There are only four chemical units in this language of instruction: A (adenine), C (cytosine), G (guanine), and T(thymine). We might think of these as "letters" in the language of genetic instruction. 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. A six-word-long strand might read as AAT-CGT-ATG-CCT-TAT-GGA, and so on. Thus, we can think of each instruction for a protein (a gene) as a collection of these words that may range from a few to thousands of words. When the term "genetic sequence" is used, it refers to identifying these strands in their proper order.



DOE Human Genome Program

The instructions for creating proteins are contained twice (but in reverse order) because they occur in a double structure that looks like a twisted rope ladder. This is called the double helix (refer to graphic). The chemical letters sit on the long bands (a different chemical substance) of the ladder's outer structure and form its rungs because each one connects with another letter on the opposite band. It is essential to note that a C will match up only with a G, and an A will match up only with a T to form these rungs (the matchings are called base pairs). In this way, each word and its exact sequence is present twice. This arrangement explains how DNA so readily duplicates its instructions. This ladder readily comes apart between the G-Cs and the A-Ts (chemically



DOE Human Genome Program

called weak bonds) in a way that visually reminds one of a zipper. The presence of a complete set of instructions on each side of the ladder means that new chemical material can be joined to either side so that two duplicate sets of instructions will be created.

The collection of genes (called a genome and containing somewhere from fifty to seventy thousand genes) is found on 46 separate sets of these double helix structures. Each of these 46 is called a chromosome. These chromosomes are found within the nucleus of most human cells. When the time is right, special proteins uncoil the chromosomes, and the rungs of the ladder split at the point where the needed instructions for that cell are stored. The protein-building process then involves a series of messengers that copy the information from its source in the gene and

activate it for "expression" (the scientific term) in such a way that amino acids are linked together in sequences which, in turn, create proteins. These proteins then carry out their function, either within the cell or by traveling to target cells elsewhere in the body. In animals these functions range from creating ligaments, to carrying oxygen, to forming chemicals in the brain.

Although science still has much to learn about these processes, current knowledge about genes is sufficient to permit us to test, engineer, and duplicate these fundamental instructions of life. We will return to the implications of these abilities. At the moment, we should explore how genes are not just instructions for proteins, but also units of heredity.

Transmitting the Genetic Information through Reproduction

When thinking about genes as units of heredity, we will shift metaphors somewhat and think of genes as the kind of instructions we call recipes. In this analogy, genes are recipes passed on from generation to generation for "cooking up" living beings. The system is complex, but it functions much like parents passing on the family's secret recipes. A critical component of this process is the variation or change that results, much like the newly combined set of recipes in the household of a newly married couple.

All living things are genetic at the basic level and share the need for some method of exchanging and varying the genetic information which is their heritage. Bees do this for flowers by the transfer of pollen. In mammals, the variation occurs when a sperm and an egg (called gametes), each containing a copy of recipes from the two different parents, combine to produce offspring with two non-identical copies of the genes.

Again, it helps to use the analogy of two sets of cookbooks, one from each parent. The cookbook in this analogy is the chromosome, which could be thought of as a collection of gene recipes. Most pages of those cookbooks, perhaps as high as 97 percent, contain gibberish (the scientific term is nonsense) that is of minimal importance or is left over from evolution. The roughly 50,000 functional genes are scattered among this gibberish and are hard to identify. Even with the HGP's work, scientists will still need years to identify precisely these recipes. In the human genome, the 46 "cookbooks" or chromosomes are numbered by their size, #1 being the largest and #22 the smallest. There are two copies of each of these first 22 cookbooks. These duplicate copies of chromosomes have a special name, called autosomes. Forty-four of the 46 chromosomes are autosomes. The remaining two are special sex chromosomes, given labels X and Y rather than being numbered. If there is one copy of the X chromosome and one of a smaller version labeled Y, the body is male—refer to the picture of chromosomes called a karyotype on page 14. If both sex chromosomes in a particular human being are the large ones, labeled X, the body is female.



The process of human sexual reproduction combines one copy of each of the 22 autosomes (cookbooks) and one sex chromosome from each parent, producing a child with 46 chromosomes, half from each parent. This regular reshuffling of the human (or any mammal's) gene pool creates continuity with variation. Additional alteration in the genes results from mutation. A mutation is a change in the DNA sequence due to chemicals, radiation, or copy errors. (We should note that mutations may occur at any time from conception onward as cells duplicate themselves.) The process of mutation is only vaguely understood, but its effects are clear. Inherited variation and mutation are the primary sources of genetic change, whether considered beneficial or harmful, and it is important to understand how this change occurs and how it effects organisms.

Understanding Genetic Change

Genes and Alleles

Two additional concepts can help us understand genetic change. The first is the difference between a gene and an allele. A gene is a sequence of DNA which encodes for a protein. Alleles are the variant forms of that gene found within a given population. They encode for that same protein, but with slight alterations. To return to the recipe analogy, we could think of a standard chocolate chip cookie recipe as a gene. Its allele would be the alteration of that recipe by a baker. Some of these alterations turn out to be flops, while others are hailed as improvements. For instance, the substitution of salt for one quarter of the recommended sugar would be an alteration making the cookie unpleasant to eat. The substitution of pure butter for margarine, on the other hand, would be considered a real treat. In genetics we call the first alteration a disease because it is harmful. In the other case, the alteration simply creates a difference that may be judged benign or beneficial. It is not always clear whether a genetic alteration represents abnormality or just diversity.

Dominant and Recessive

The second concept involves dominant vs. recessive genes. Recall that there are two copies of chromosomes 1 through 22 in each cell nucleus. Therefore, there are two copies (two alleles) of each gene on those chromosomes. In some cases, one abnormal allele is enough to cause trouble in a body despite the presence of the normal one. If so, the abnormal allele is called *dominant*. In other situations, the one good allele works well enough and the abnormal allele and its consequent condition, trait, or disease are termed *recessive*. For recessive conditions, the disease appears only if both alleles are abnormal. The person who has one normal and one abnormal allele of a recessive condition is called a carrier.

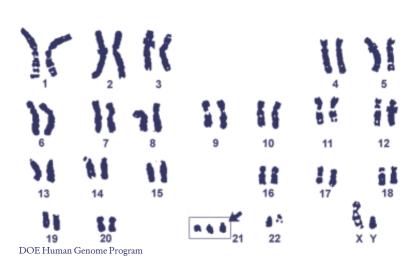
All humans carry about a half dozen lethal recessive alleles (from among their approximately 50,000 genes) that are hidden by the good copy. Every human then is a carrier of lethal diseases. These abnormal alleles do not cause problems unless that individual happens to mate with someone else carrying a lethal allele of the same gene. Incest and inbreeding are more likely to produce a match of two such recessive alleles due to the increased chance that both partners carry the same recessive allele.

Genetic Errors

Just about anything imaginable can and does go wrong in transmitting genetic information. Using the encyclopedic cookbook analogy, whole volumes may be missing or they may get put together incorrectly. Recipes don't get copied. Words get misspelled and letters get deleted. Nature is an excellent typist, but the genome's three billion base pairs are 200,000 times longer than this chapter. This genome is copied perhaps several trillion times from conception to death. Indeed, about 100 billion cell divisions are necessary each day just to replace cells lost to normal wear and tear. Mistakes are bound to occur, from conception onward, and some are lethal. In fact, it is estimated that 60-80 percent of all human conceptions die before birth, most within the first two weeks after conception, largely due to genetic errors. This phenomenon is called fetal wastage. In some cases, the embryo survives genetic abnormalities, but the individual will have many health problems, ranging from mild to severe.

For simplicity's sake, we can divide these errors into two major types. The first is chromosome errors. Sometimes whole or partial copies of chromosomes may be missing, joined incorrectly (called translocations), or have extra copies. Generally speaking, embryos with these errors do not survive to birth, but there are a few exceptions, the most widely known being Down's Syndrome. A child with Down's Syndrome has a third copy of chromosome #21 (see karotype image on page 14), which is characterized by

slanting eyes, a large tongue, and mild to profound mental retardation. The second category of errors involve genes, either single or multiple ones (called multi-factorial syndromes), and there are several types of errors in each case. The following are representative examples and illustrate both the importance of alleles and how diseases can be either dominant or recessive.



Single Point Deletions or Mutations Cystic fibrosis is a recessive disease caused by the faulty production of a single protein that regulates the movement of chloride ions through cell membranes. This results in excessively thick and sticky mucus that encourages lung infections and digestive problems. The most common genetic error is an allele called delF508. This means that the 508th word in the recipe is missing. As a result, the protein is missing a single amino acid, labeled "F" for short. From a necklace 1,480 beads long, only a single bead is missing, but this tiny change leads to cystic fibrosis. While this delF508 allele is present in three-fourths of all children with cystic fibrosis, the other fourth is caused by various

other alleles. Despite the media's use of the term, there is, therefore, no such thing as a "cystic fibrosis gene." Rather, there is a gene for a particular lung cell membrane protein, and it has many variations, some of which cause cystic fibrosis. If both alleles (the particular copies of that gene in an individual) are delF508 or another harmful variation, then the child will have a disease called cystic fibrosis.

Even the misspelling (mutation) of a single letter in a single word can produce disease. In sickle cell anemia, the allele of a gene that codes for hemoglobin (the red oxygen carrying protein in the blood) contains a variation of the middle letter of the sixth word of the recipe (the middle base pair of the sixth codon of the gene). In this variation, a different amino acid is inserted into the protein as it is made. This variation of amino acid changes the solubility of the hemoglobin, which leads to symptoms such as severe joint pain, shortness of breath, increased infection, and anemia. These are all due to the effects of the impaired delivery of oxygen to tissues that need it for normal functions.

Multi-factorial Syndromes

Many syndromes and diseases are caused by more than one gene. News media often report the discovery of a "gene" that causes a common problem like alcoholism or Alzheimer's disease. Yet a gene identified as the "cause" of early-onset Alzheimer's accounts for only a small fraction of all Alzheimer's cases. Science has yet to determine even what approximate combination of gene and environment account for these other cases.

Promise and Perplexity

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 how the world of living creatures works, about disease, plant reproduction, and many more. This knowledge then allows—in theory at least—human beings to manipulate these sets of basic instructions upon which living beings depend. This is awesome power. A convenient way to divide these powers is diagnosis, engineering, and duplication (cloning). We shall briefly expand on the promise and the perplexity that attends each.

Diagnosis, usually call genetic testing, can be broken down helpfully into several categories. These include: Onset of life, adult-onset, and criminal or work place testing. The most common form of genetic diagnosis involves the unborn or newly born. Currently, screens or tests are available for only a handful of possible, if significant, disorders. Hundreds of more tests, when developed, could be used since much (not all) of an individual's genetic instructions are in place after conception. Testing at the onset of life also includes carrier testing. (These terms are explained in the chapter entitled Genetic Testing at the Beginning of Life—see page 26.)



The testing of adults is possible to indicate future illness (Huntington's disease—see glossary for explanation) or, more commonly, the propensity for illness (for example, forms of cancer or heart disease). Such testing could be used in the workplace to identify those individuals, for instance, with a propensity to develop cancer in a toxic work environment. Finally, since each individual's genome has a genetic "finger-print" (enough slight variations in base pairs to make it unique), a hair strand or bit of saliva from a crime scene can identify those who were present.

Genetic engineering is a term used in several ways. In this guide the definition is a broad one that means any process of manipulating the patterns of proteins in an organism by altering DNA sequences. This includes attempts to alter existing ones or to add new ones. The goals of such engineering range from medical to agricultural ones, but the common purpose is to change the way, amount, timing, and so forth, in which proteins are made.

A medical form of engineering is experimenting with the "correction" of disease-causing alleles by retrofitting (inserting back into place) non-harmful sequences for the harmful ones. One such experiment involves inserting non-cancerous genetic instructions into cancerous cells with the hope of replacing the cancer producing genetic sequence.

A major distinction in therapy is made between "correcting" somatic cells (body cells that will die with the individual) and altering germ cells (an individual's cells for sexual reproduction). Changes to germ cell alteration would be passed on to offspring. This kind of alteration obviously is more questionable because of the long term and unknown consequences.

Other forms of genetic engineering include efforts to insert foreign genetic material into a genome. Some instances alter only short segments of a genome; for example, the insertion of pest-resistant genes into soybean or corn seed. Other instances alter a genome dramatically by splicing it with significant pieces of foreign genetic material. In theory genetic engineering could be practiced on plants, animals, their embryos, and on humans who are indeed part of the animal kingdom. It is important to stress that much more has yet to be learned, but theoretical possibilities exist for large-scale alteration. In practice, most engineering thus far has focused on producing commercial products, such as new forms of seeds for farmers.

The widely discussed *cloning* of Dolly (sometimes called the "sheep heard round the world") represents an additional set of challenges. To clone means to reproduce the genome of a living organism, which then results in a nearly exact replica. The most commonly seen—and natural—form of cloning is that of identical twins: two individuals from one genome. The term "cloning" in public discussion is often used to indicate the reproduction of an adult genome, as in cloning a movie star's genome. Yet, it is important to distinguish, broadly speaking, three kinds of cloning: DNA (a gene or segment thereof), twin (as in splitting a cell or early stage embryo into multiples), and somatic nuclear transfer (the technique that produced Dolly).

The benefits of genetics for human endeavors, from medicine or agriculture, have been hinted at throughout this discussion. The difficult questions have also been just below the surface. What are the special dilemmas that arise when we know about incurable diseases before the birth of a child or before they occur in an adult? How shall we avoid discrimination based on genetic heritage? Is human behavior determined by our genes, just like hair color? Should we modify food sources? How much modification is safe? Should we engineer genes in a way that will have long-range impact, as in germ-line therapy or in the creation of new seed forms? Should we engineer "designer" children to fit parental desires? Who should regulate these practices, and how much? What should the church say in all of this? Questions such as these will be the concern in later chapters.

Discussion Starter

Whatever one's level of genetic knowledge, each of us approaches today's genetic developments with a set of preexisting judgements. These judgements are based on personal experience and values. They may be firm or quite malleable, but they exist. We might characterize the range of possible judgments in this way: a) unconditional acceptance; b) general approval; c) hesitant acceptance; d) critical engagement; e) charitable negation; f) resolute rejection. Of course, these categories are not precisely defined. Moreover, each person likely will find his or her view shifting a bit on the spectrum according to the specific purpose,



technology, or impact involved. Nevertheless, thinking about such categories can aid in gaining valuable self-understanding of where one stands. The end of this chapter is a good time to consider the initial judgment you bring to the study of genetics.

The question to reflect upon is: Given what you know of genetics, which category on the spectrum best describes your judgment toward the potential benefits and dangers of genetics? An awareness of this judgement will be significant in considering the various topics in subsequent chapters.

For Further Investigation

Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science. Roger A. Willer, editor (Kirk House Publishers, Minneapolis, 1998) Copyright held by the Evangelical Lutheran Church in America. Several sections in Genetics 101 above were adapted from the chapter by Kevin Powell, M.D., Ph.D. in this book. His chapter is an excellent place to seek additional explanation.

Several Web sites with excellent introductions to genetics are also available. The ones listed here include two government sites. (Inclusion on this list represents no recommendation of these sites over others that are available.)

www.ornl.gov/hgmis/project/info.html

www.ornl.gov/TechResources/Human Genome/home.html

www.biology.about.com/science/genetics/cs/basicgenetics/index.htm

Citations

1. "Human Genome Project Information," The Human Genome Program of the U.S. Department of Energy, <www.ornl.gov/TechResources/Human_Genome/home.html>.



Chapter Two—Theology for the Age of Biological Control

"You have great knowledge, Dr. Carter, [said Ezekiel] some say genius. But it takes more than knowledge to be God. You need wisdom. . . . [Just think about a] world in which anybody could heal everybody, and no one ever died of natural diseases. Imagine a world where there would be no consequences for any actions we took. A world with such an enormous population that instead of a heaven on earth we would create a living hell. No space. No food. No respect for life—or death—and certainly not God. Just a crowded desert of lost souls assured of only one certainty—a long life. . . .

"Tell me, Dr. Carter," continued Ezekiel, "does wanting to save your daughter, one insignificant human in a sea of humanity give you the right to play God? Does it give you the right to risk creating a hell on earth?... You had no right to use your intelligence and resources to change that. And that applies to the others you have saved with your meddling genetics...."

(From a conversation between the leader of a religious sect [Ezekiel] and a geneticist [Dr. Carter] in the novel *The Miracle Strain* by Michael Cordy)¹

"In many ways Michael West is the shadow impresario of the field. As founder of Geron Corporation, one of this decade's most closely watched biotechnology companies, and now as president and CEO of Advanced Cell Technology, West has achieved remarkable success as a kind of merchant of immortality, selling the idea that stem cells and related technologies might someday completely revise the tables of average human life span. . . . Thus, in November 1990, he founded a company dedicated to the molecular causes of aging. He named it Geron—Greek for 'old person.' He eventually captured the interest of the most prestigious venture-capital firm on the West Coast, Kleiner Perkins, Caufield & Byers, which along with other firms invested \$7.6 million in Geron in 1992. . . . In both technical articles and news releases, it has retailed a scientific vision (and vocabulary) that clearly push the right zetigeist buttons. West and Geron spoke tirelessly of 'immortalizing enzymes' and the 'life extension' of cells. . . . "

(From "The Recycled Generation" by Stephan S. Hall, New York Times Magazine)2

Introduction

The quotes above point toward two very different views on the genetic developments that are moving us into what may be called the *age of biological control*. The first view, sometimes summed up by the phrase "playing God," fears the outcome of tampering with genetic nature. It expresses great doubts about human ability to use this new knowledge in a humane fashion. The second view confidently celebrates a vision of how genetic developments will aid the human race. This vision includes vastly improved health care, greater control of human destiny, and economic benefit. It may be that both of these opposing statements contain important insights, but clearly, people of faith are called to the task of thinking beyond any immediate reaction to genetics, whether pro or con. Such careful and critical thinking that begins in faith and uses the resources of a faith tradition is called theology. Theology is, after all, sustained and orderly thought about life under God from the standpoint of faith. In this sense, this study guide invites every reader to be a theologian.

This chapter's purpose is to provide material for theological thinking that can respond constructively to issues raised by genetic developments. Two questions and two types of reflections will drive this task. The first question is about the kind of society in which we live and invites a theologically based analysis of our culture. Such thinking raises additional quandaries to those already posed in chapter one about the potential impact of genetics on personal lives and the social order. For instance, could the kind of society itself in which we live lead to the misuse of genetic knowledge despite good intentions on the part of science and medicine? In probing these ideas, the important concept of "mindset" (the intellectual assumptions a person brings to any topic) is developed. We will also recall how our society in the past attempted to



"improve" the human gene pool. We will probe such issues as American individualism and *genetic essentialism* because they are part of the cultural context in which genetic knowledge and power are being developed.

The second question asks, What are the theological resources that Christians might specifically call upon to aid their thought and action in an age of biological control? The broad ideas offered are not definitive blueprints for response, but they do suggest key Christian themes that are developed with genetic challenges in mind. They are what might be called the "base points" from which to engage genetic questions; these fundamental ideas can form a valuable framework for thinking about the subsequent chapters.

Personal Experience and Values

Each person approaches genetics—or any topic—with a broad and pervasive set of beliefs, knowledge, experiences, commitments, emotions, and judgments. These can be called *pre-understandings* and they form the context that a person brings to what they learn, and do. Each person's pre-understandings are influenced by, among other forces, the broad intellectual ideas of culture. We shall call these broad ideas *mindsets*. Indeed, there are several different social mindsets contending for allegiance in our society, and each person may experience conflict among them. Because these mindsets are so important, it helps to explore some key beliefs in one's mindset even before we reach the subject matter.

One aspect worth thinking about is the role that religious ideas should play in matters like business and medicine. For some individuals, there is an unbridgeable chasm between Sunday worship and Monday workday thinking. Some of these individuals see this as acceptable and fortunate, while others

"... this new scientific knowledge alone will not answer the deeper, philosophical questions that have plagued humankind for centuries. What does it mean to be 'created in the image of God?' What is the relationship of humankind to the rest of creation? Pondering the worthiness of humankind, the psalmist rhetorically asked God, 'What are human beings that you are mindful of them?' (Psalms 8:4). The answer to these questions does not lie in our genetic sequence. But unveiling the sequence may profoundly impact our understanding of those questions."³

Kevin Powell, pediatrician From *Genetic Testing and Screening*

see it as unavoidable and unfortunate. A different view is that the gap is bridgeable and that religious ideas can help bring great clarity to decisions in business or politics. What is your view about the relationship?

A second consideration is one's perspective on *individualism*. Some argue that individualism has run rampant in United States culture, while others believe that the more individualism we encourage, the better. One way to gauge one's view on this is to reflect on which slogan seems more appropriate in motivating service in the armed forces: "Be all that you can be" or "Do your duty to your country." What perspective do you have on individualism in the United States?

Gathering Insight

Theological Social Analysis

There are many reasons why people are concerned about the misuse of genetic knowledge and power. Some of the challenges and the related concerns were highlighted in the first chapter. Additional concerns appear when we think about genetic developments and culture. This section will focus specifically on the mindsets of progress, individualism, and *biological essentialism*.

One reason for concern today is the track record of genetics in the recent past. Nearly a century ago, a previous wave of genetic advancement brought with it a frightening social movement called *eugenics*. Eugenics literally means *good genes*, and it was based on the genetic theory of that time with the stated intent to improve the health, fitness, and intelligence of the human race. Eugenics is usually associated with German Nazism, but it developed first in England and was widely influential in the U.S. until the late 1930s.

The movement was carried forward in the name of progress and was composed largely of people from the white middle and upper middle classes. Its practices were endorsed at the highest levels of society, including state legislatures and the Supreme Court.⁴

The goal of this eugenics movement was the prevention of social degeneration through both "positive" manipulation of human heredity and "negative" elimination of the inferior. Widespread positive eugenic practices included "fitter family" contests at many state fairs to encourage people to breed wisely. Negative eugenics included forced sterilization, a practice legalized in more than 20 states and used on thousands of prison inmates, the "feeble minded," and poverty-stricken women of selected ethnic groups. Opinion in the U.S. turned against eugenics in the 1930s because of its growing association with Nazism and because its genetic theory proved faulty. When it became clear that the mentally retarded could have children of normal intelligence, the eugenic movement's assumptions were disproved. Few social analysts today forecast a return to such eugenics, but many raise concerns about new forms of eugenics driven by the free market economy in tandem with parental choice. In particular, many worry that extreme forms of American individualism offer the perfect environment for fostering a new eugenics. The idea of this individualism is characterized by the claim to personal autonomy and control, and is supported by the notions of self-reliance and privacy. This individualism sees community as secondary, as a necessary convenience created by a *social contract*. In this view, the individual comes first. An illustration of an opposite point of view is the Bible's perspective in which the community comes first. It is from community that individuals emerge. Thus, one's first loyalty is to God's community.

"Yet I forecast that a new form of eugenics may eventually come upon us at gale speed. Like moving air that is invisible to the eye, at first we will feel but not see eugenic winds blowing from two directions: first, discrimination in health insurance and employment; then, secondly, personal tastes for designer children accompanied by the rise of the *perfect child syndrome*. I forecast that these winds will advance to gale or hurricane force, and future children will walk in the debris of the coming storm over selective abortion." 6

Ted Peters, theologian
From Genetic Testing and Screening

Ethicist Hans Tiefel has pointed out that individualism has brought many gifts to Western society, including the central insistence on dignity and worth of the individual. But he also notes its many dangers in the extreme form he calls "American Individualism." This extreme individualism looks to the self for the meaning of life and for moral virtues, thus stressing sheer self-realization, self-reliance, and so forth. It is exemplified in the growing insistence on private choice and can lead to the belief that moral decisions should be made only in terms of self-satisfaction. It is captured by the phrase, "Do your own thing." The notion that aging parents or an ailing child impose on one's freedom illustrates this mindset. Such extreme individualism, Tiefel believes, contradicts biblical notions which stress the good of human community as primary and fundamental.

Tiefel is concerned that in debates about reproductive choices, the individualistic notion of privacy has

become absolute. This can lead to a situation in which the only criterion for such choices is whatever the "market will bear." In other words, if a reproductive technology can be successfully marketed, then it will be. The result may lead parents, who want only the latest and best for themselves, to engage in genetic selection and the practice of *designer babies*—a new eugenics.

A related cultural mindset worries ethicist Elizabeth Bettenhausen, the view she calls "biological essentialism." This is the idea that DNA defines the essence of the human being. For example, some scientific studies have blamed poverty or criminality on genes. Others have blamed low intelligence on the genetics of race. These kinds of claims are dangerous because they allow racial and sexual categories or social problems to be blamed on genetic sources. In other words, categories or problems that are actually social in character are now passed off as the work of nature, about which little can be done.

Bettenhausen also sees the same essentialism at work in the way some geneticists or the media use highly religious language to spiritualize the human genome. DNA is described as the location of the true self or talked about as the soul of the individual. Some scientists talk about the effort behind the Human Genome Project (HGP) as the search for the "Holy Grail," or as the decoding of the "Book of Man," or as the knowledge of the "Second Adam." This, she warns, leads to human arrogance and the reduction of the complexity of a human being.



Elements for a Theological Framework

How should Christians respond to these and any other mindsets that encourage the misuse of genetic power and knowledge? Clearly, the dangers as well as the promises of genetic developments require thoughtful responses.

Critical Engagement

The Evangelical Lutheran Church in America (ELCA) has not established an official position about any genetic issues as of this writing. However, a book (titled *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*), commissioned by the ELCA's Division of Church in Society, suggests that an appropriate response to genetics is the stance called *critical engagement*. The book is devoted to genetic testing and screening issues, but the ideas may be generalized.

The designation *critical engagement* means, first of all, that the only satisfactory way to approach genetics is by openly engaging the scientific, medical, and economic knowledge involved. This view assumes that legitimate and important two-way connections exist between Monday morning talk and Sunday morning language. Further, it entails the conviction that Christians must intentionally think through genetic issues. An uninformed rejection or complacent acceptance is not an adequate response. Critical engagement further signifies that the emerging genetic knowledge and its application are to be affirmed in principle as means to aid human endeavors for healing, etc. At the same time, it holds that people of faith must *critically* consider each specific use according to judgments informed by faith and Christian sources. This will mean that Christians sometimes resist a particular use of genetic technology while encouraging its use in

This view depends on several commitments. The first is that genetic developments are understood as

occasions in which God as creator is at work. Thus, gratitude and religious concern are appropriate responses. However, it recognizes that sin is just as assuredly present in this human enterprise. Therefore, overblown pride in these abilities is not appropriate. Mindful of both beliefs, and because God encounters us precisely in such ambiguous situations, we are called to be attentive to God's presence and will as they develop.

Six Theological Convictions

Theological ideas that undergird such convictions are fleshed out by Philip Hefner as elements in a theological framework for the ELCA's book mentioned above. They are delineated below to help suggest how Christian faith offers simultaneously both a resource and a challenge for a critical engagement of genetics.¹²

- 1) Hefner suggests that Christian faith should see *genetic developments as a kind of sacred space*, a place in life in which to meet God and discover the meaning of Christian faith. This is because God comes to human beings only in such real-world places. The *challenge is to avoid idolizing genetics* while recognizing that God dwells with us in such ordinary places as the medical office or the biotech board room.
- 2) Christian faith provides an umbrella story under which all of human experience unfolds. The narrative of God's creation, redemption, and intended fulfillment of the universe provides the means to integrate the experiences we bring to the issues of everyday life, including those of genetics. The center of the story is Jesus Christ who is, on the one hand, the one in whom all alienation and guilt is reconciled, but on the other, who is also the model of the form that human nature should take. This story places human beings firmly as natural creatures who yet have accountability for their actions in relation to all of nature.

"If the church chooses to be present to people struggling with genetic choices, it must become genetically literate in order to understand and respond. Science and technology have brought us into an erawhich requires profound responsibility. For Christians, this is not an affliction but a gift from God. This gift offers opportunities for great good or for radical abuse. God has given us the freedom and responsibility to make such decisions. Christians are called to participate in genetic decision-making, both in personal and societal realms. As servants of Christ and stewards of the mysteries of God, (I Corinthians 4:1), this responsibility requires preparation."11

Kirstin Finn Schwandt, genetic counselor From Genetic Testing and Screening

- 3) Christian faith speaks of the *goodness of creation in the highest terms*. It does so because God creates the universe, affirms it mightily through the incarnation of Christ in creation, and promises to bring it to fulfillment. Thus, humans can celebrate being part of the creation into which genetic knowledge gives us insights and over which it gives us power. The challenge is that Christian *faith will not tolerate any intervention into nature that looks upon it as a personal belonging* or believes we may do whatever we want with it. Rather, nature belongs to something greater than our design and we are accountable to this greatness that we call God. To know that the infinite God is present in finite nature is, therefore, to have a resource for critique of arrogant pride with respect to any use of nature.
- 4) Christian faith perceives humans as shapers of nature. Genetics continually raise the question: "What is the purpose of our activities to intervene in nature or to shape it in a particular direction?" "Why should we do this or that?" Christians have no blueprint answer, but the Christian story does insist that humans are on earth in order to glorify God, the Creator. It further holds that the thrust of any action, including genetic developments, should look something like that of Jesus Christ. This includes the centrality of self-giving for the benefit of creation and its people. Thus, Christian faith will question any genetic intervention that is an end in itself or whose priorities are not the common good of society or of nature itself.

"God has endowed us with the freedom and power to make decisions, but has not endowed us with the wisdom to see all of the possible contingencies in the future, nor the power to guarantee the outcomes we intend. And, as we know from personal experience, every decision has an infinite array of potential outcomes that we humans can never fully know or anticipate. That is part of the agony of decision making: to have responsibility without full knowledge and empowerment." ¹³

Larry Holst, chaplain From *Genetic Testing and Screening*

- 5) Christian faith acknowledges finitude, ambiguity, and failure. Christian faith insists that sin or finitude do not negate the worth of human effort. No matter how full of sin and vulnerability, human efforts do make a difference. They are part of God's work, even if we cannot be sure how God will use them. Further, Christian faith will not avoid the prospect of death and its meaning. The challenge here is that all efforts, including medical intervention, are tainted by sin. However, even as Christian faith subjects human pride to critique, it equally motivates Christians to lives that go beyond inaction to attempts at healing and care.
- 6) Finally, Christian faith proclaims that in Christ, we as his people are not only anguished, bewildered, limited decision makers; we are also redeemed decision-makers. In the final analysis, this is Christian confidence. Decisions may never

be free of sin, but as Christian decision-makers, we need not fear that only righteous deeds will somehow make us right with God.

Chaplain Larry Holst, writing near the end of this same book, summarizes well this critical point. Our redemption, he writes, "does not lessen moral accountability to choose as wisely as possible and work as hard as possible. Luther once advised Christians "to sin boldly." But he added: "Rejoice in Christ even more boldly for He is victorious over sin, death and the world." Luther here is advising us to discern carefully our moral situations, then decide and act with boldness. This boldness is rooted not in the infallibility of our moral discernment but in God's sustained forgiveness. Because of this, we Christians must always co-mingle human responsibility with God's mercy. That call to responsibility linked to that mercy is the greatest resource Christians have to pick up the burden of critically engaging the unprecedented decisions and powers that genetic developments place before our society."¹⁴

Further Reflection

The following is a list of major issues presented by genetic developments to society. ¹⁵ (Many of these will be addressed in later chapters in much greater detail.) As a person of faith, consider which ideas from the theological analysis above would bear on these challenges. Remember that these ideas will not provide immediate solutions, but they will help provide general base points from which to consider these challenges. These ideas may also aid in sorting out mindsets unacceptable to a faith-based perspective.



- Genetic discrimination: Should a person's genetic information be available to insurance companies or to employers, or others? Could genetic information become the next form of discrimination?
- The abortion controversy: This divisive issue becomes more complex and extensive with genetic knowledge involved. (Chapter 3)
- Patenting creation: Which genetic information should be patented? Human genes? Plant genes? Genetic processes? (Chapter 5)
- Genetic determinism and human freedom: Is DNA a puppeteer who determines who we are? Does a genetic disposition to something like alcoholism remove responsibility? (Chapter 4)
- Germ-line intervention: Should humans repair or "enhance" genetic material that will be passed on to offspring? Should they do this in food? In human beings? (Chapter 6)
- The church's role: What should the church's public stance and contribution be in these matters? What role should individual Christians and congregations seek to play? (Chapter 7)
- Cloning: Should we clone human beings? Should we clone animals and plants?

For Further Investigation

Burgess, John P. In Whose Image? Faith, Science, and the New Genetics (Geneva Press for the Office of Theology and Worship, Presbyterian Church—U.S.A., Louisville, 1998). This text represents the fine effort of another national denomination to address several broad theological issues raised by genetic science and technology.

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- **6.** Ted Peters, "Love and Dignity: Against Children Becoming Commodities." *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, ed. Roger A. Willer. (Minneapolis: Kirk House Publishers, 1998), 117.
- 7. Hans O. Tiefel, "Individualism Vs. Faith: Genetic Ethics in Contrasting Perspectives." *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, ed. Roger A. Willer. (Minneapolis: Kirk House Publishers, 1998), 131.

- **8.** Elizabeth Bettenhausen, "Genes in Society: Whose Body?" *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, ed. Roger A. Willer (Minneapolis: Kirk House Publishers, 1998), 104.
- 9. Ibid., 113.
- **10.** A social statement on health and health care issues is in preparation as of this writing. The current timetable calls for the ELCA Churchwide Assembly of 2003 to receive that statement for adoption. Several issues in that statement may well impinge on concerns related to genetics.
- **11.** Kirstin Finn Schwandt, "Personal Stories: Cases From Genetic Counseling." Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science, ed. Roger A. Willer. (Minneapolis: Kirk House Publishers, 1998), 56.
- **12.** Philip Hefner, "The Genetic "Fix": Challenge to Christian Faith and Community." *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, ed. Roger A. Willer. (Minneapolis: Kirk House Publishers, 1998), 84f.
- **13.** Lawrence E. Holst, "A Pastoral Perspective: Companionship Beyond Innocence." *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, ed. Roger A. Willer. (Minneapolis: Kirk House Publishers, 1998), 186.
- **14.** *Ibid*., 187.
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Chapter Three—Genetic Testing at the Beginning of Life

Some blood had been drawn during Sarah's regular visit to her doctor about a week ago when she was 16 weeks pregnant. Sarah was anxious about the results, but her obstetrician had told her not to worry. If the screen showed an abnormality, she could learn more about it at that time. When her doctor called her that evening, she could tell

Edwards Syndrome (Trisomy 18)

A syndrome associated with the presence of an extra (third) number 18 chromosome. It occurs in approximately one of 8,000 live births and involves multiple abnormalities. Common characteristics include low birth weight, mental retardation, low-set and malformed ears, small jaw, hand abnormalities, congenital heart disease, hernias, and others. Few infants survive beyond the first year.

by the tone of his voice that something was wrong. "Sarah," he said, "the results of your triple screen have come back 'screen positive.' You might want to consider having amniocentesis performed." He then gave her instruction about how to proceed. Sarah did not hear much else that he said other than the fact that her baby might have something called Trisomy 18, also known as Edwards Syndrome.

The next morning Sarah called for an appointment and was told that she needed to see a genetic counselor. She had no idea what that was, but she managed to get an appointment for that afternoon. Her husband, Allen, took off work so he could join her. At 3:00 p.m., they were introduced to Jill, the genetic counselor. Jill explained to them that the

triple screen results indicated a slight risk that their baby might have Edwards Syndrome. Only an amniocentesis could determine it definitively.

As they talked with the genetic counselor, it dawned on them that having had the triple screening, they were now confronted with whether or not they should pursue having a test to determine, before the birth of their baby, if it had this condition. Sarah was not sure she wanted to know. Allen, on the other hand, was wondering if the anxiety of not knowing would be too much to think about for another five months. Together they discussed with the genetic counselor whether or not they might think about termination if they found out the baby had Trisomy 18. Sarah and Allen had never even thought about it. They were not sure what they would do. They did not even really know what children with Edwards Syndrome were like.

Genetic Counseling

Genetic counselors (a relatively new profession) hold a master's degree that prepares them for counseling patients undergoing medical procedures involving genetics. A genetic counselor follows a few basic tenets. These include respect for autonomy and privacy of the individual, the need for informed consent and confidentiality, and the goal of nondirectiveness. Sarah and Allen were overwhelmed at the thought of having to make the decision whether or not to terminate a much-wanted pregnancy. Jill suggested they think about the amniocentesis more before coming to any conclusion. That evening the couple talked more about the triple screen results, now armed with enough information to make an educated decision. In the end, they decided they would go through with the amniocentesis. When they had the chromosome results, then, and only then, would they be able to think about what they should do.

The amniocentesis was performed two days later. Allen and Sarah waited impatiently for the results of the chromosome studies. As far as they were concerned, life could not go on until they had the answer. The genetic counselor called them

early the next week. "I'm sorry I have to give you this news," said Jill. "I know you were hoping to be reassured by the results. The baby has an extra chromosome 18. This confirms Edwards Syndrome. . . . "

Sarah was devastated, even more so than when she had received the results of the triple screen. Jill suggested that she and her husband come for another appointment. Sarah agreed. She knew the information about the condition would be beneficial, but she also wondered how much she really wanted to hear it at this point.



The couple tried to think of others with whom they might be able to talk. They had little previous preparation for making this decision. They knew that this information could help them prepare for the birth of their baby with a severe abnormality. But the news also had introduced abortion as an option. Or, could they look into adoption? What should they do? What did their faith tell them to do? Since Sarah was 18 weeks along in her pregnancy, they had only a few weeks to make a decision....¹

Introduction

Medical genetic testing has been the most prevalent way in which "genetics" has affected the immediate lives of people today. The use of the triple screen mentioned above represents a prime example and the expanding knowledge of genetic science will

permit the development of dozens of tests and screens for other syndromes or predispositions to disease. It is important to divide these tests between those associated with the beginning of life and adult testing. This chapter considers the first while a later chapter will explore the second. The tests related to the beginning of life can be broken down further into prenatal, neonatal (newborns) and carrier testing (see sidebar for further explanation). Attention here will be directed largely to the first and third category because they pose the most troubling questions. The case of Allen and Sarah will help illustrate what could become a common part of the parenting experience. The purpose is to help the reader better understand and reflect upon the complexities posed by these uses of genetic testing. Attention will center on several of the following questions.

Genetic testing is offered or even encouraged because it permits, like other medical tests, greater information and choice. This information can be exceedingly useful. Yet, some critics contend that often genetic knowledge creates the "illusion of choice" and makes all pregnancies tentative. Pregnancy becomes tentative because it is increasingly difficult for prospective parents to commit themselves to an unborn child before a diagnosis is offered. These critics argue that such important decisions are truly free only after a commitment has been made to the unborn. In this sense, medical technology has actually set up a bias, even though it is seemingly neutral. If this is true, should medical practice be altered in some way?

Yet the dilemmas can predate pregnancy. If family history warrants it, prospective parents can have carrier testing done in order to determine whether or not they carry certain inherited conditions that

could affect their offspring. (See sidebar for examples.) Since most of these conditions are recessive, however, carrier tests often can indicate only the statistical chance for an offspring to suffer from that condition. It is quite possible, increasingly so, for prospective parents to face the following dilemma: Should we avoid conceiving a child because as carriers we have a 25 percent chance of having one with a problematic medical condition? Or should we conceive, but anticipate an abortion if the odds go against us?

The related and obvious question is that of abortion. Should it ever be performed in these cases? Could aborting the pre-born, known to have a severe condition, ever be the loving thing to do? What are the criteria?

About Tests and Screens

The procedures of testing and screening are often blurred under the term "testing." A test, technically speaking, is a procedure to identify specific information about an individual's DNA or the specific proteins it produces. Screens, by contrast, are a population-wide procedure that look for telltale products of genetic material known to cause disorder. The triple screen mentioned here looks for signs of three genetic disorders by identifying proteins in a blood sample of the expectant mother. The findings of a screen often include false positives, and only an additional test of the fetus' chromosomes can be determinative.

Categories of Genetic Tests

Medical protocol offers *prenatal* screens or tests early in a pregnancy when certain conditions such as advanced maternal age or ethnic disposition are present. Such screens or tests look for telltale indicators of such conditions as Edwards or Down Syndrome. *Carrier* tests are done before pregnancy. The testing of high-risk ethnic groups are examples, including African Americans (sickle cell anemia), Scandinavians (cystic fibrosis), and Eastern European Jews (Tay Sachs). *Neonatal* testing is exemplified by the screen used to look for possible signs of Phenylketonuria (PKU) in newborns. (See glossary for descriptions of these in medical terms.)

Genetic testing adds increasing pressures to have a "perfectly healthy" baby. If testing is easy, abortion available, and social pressure strong, will that result in social discrimination against even mildly "imperfect" children? To take a specific case, could governmental and charitable dollars disappear for families raising children with Down's Syndrome? Will, or should, insurance companies refuse to provide coverage for those with pre-existing "expensive genes?" Such cases of refusal have been reported.²

Finally, what are the pastoral and congregational challenges here? Could Allen and Sarah go to a pastor and receive the kind of sensitive and informed attention they need to help sort out the issues? Would this couple find support in most Christian congregations? Would they find acceptance even if they decided to have an abortion?

Personal Experience and Values

Each one of us confronts challenges like those faced by Sarah and Allen with a backpack full of personal experiences, emotional responses, values, and judgments. These are related to upbringing, economic class, race, and other factors of our lives, and are sometimes called "pre-understandings." The point is that every person brings such pre-understandings to any issue and it is important to become aware of them within oneself. This awareness will permit a more open reflection or discussion. The following are a couple of important questions to reflect upon when engaging this topic.

What experience do you bring to the question of whether or not the use of medical technology can set up a bias? Have you had any experiences similar to Sarah and Allen's in which you have felt entangled by the choices shaped for you by medical knowledge or technology? Consider how medical technology has changed your life. In your judgment: *Is medical technology truly neutral, or can it involve unintentional bias?*

Because few cures exist for many prenatally diagnosable diseases, it is impossible to separate genetic testing from the issue of abortion. Clearly, abortion is one of the most divisive issues in contemporary society, and Christians will have very diverse perspectives and strong emotions about it. Constructive discussion about such a challenging issue begins with awareness of one's own perspective and the search to understand others' perspectives, even when drastically different from one's own. What convictions do you bring to this topic?

Gathering Input

Science and Medicine

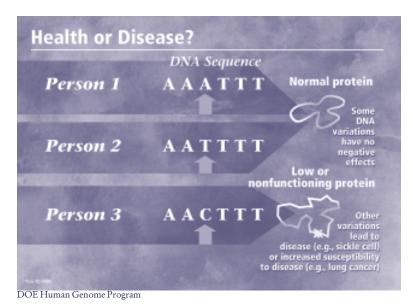
Much of the technical and scientific information needed for understanding these issues was covered in the chapter entitled *A Primer in Genetics*. A return to that chapter may refresh your grasp of genes, alleles, and other concepts. However, several additional points about genetics will aid in understanding the complexities of these issues. The first concerns why genetic tests often cannot give definitive answers, and the second how genetic tests can be used.

Gene Functions are Complex

While a gene or combination of genes that create a specific condition may be tested, in many cases, the test cannot predict the exact severity. One dominant reason for this is that mutations occur in a variety of configurations, and the actual expression (the process by which a gene's coded information is translated into a body's actual functioning) of any given gene can vary greatly. The graphic on the next page demonstrates how variations at different locations on the same gene can lead to a wide range of effects. (Some genes are known to have more than 300 different variations.)

This fact adds significant ambiguity to the factors parents have to weigh when considering the results of a genetic test. This should remind us that genes are extremely dynamic. Mental, behavioral, and even physical characteristics of a child depend for their development and expression on environmental and social factors. Geneticists indicate this in two ways. They talk about the importance of *penetrance*—a term meaning the likelihood that a given gene will actually result in disease. They also make a distinction between *genotype* and *phenotype*. Genotype is the actual genetic material carried by an individual, whereas phenotype is the observable expression of a genetic characteristic that results from the interaction of a gene with its environment.





In carrier testing, the reason that tests cannot give clear-cut answers requires a review of recessive and dominant alleles. The graphic below indicates why even an affirmative test response can result only in a statistical knowledge. Both parents are known to be carriers of a recessive gene disease (cystic fibrosis, for instance) and thus half-shadowed. Neither shows any sign of the disease because a normal allele ("A") functions perfectly well, but each also carries one altered allele ("a"—the recessive gene). Therefore, each child they conceive will receive one out of four possible combinations of their genes (AA, Aa, aA, aa). One combination could be a double set of recessive alleles (aa), and this child will be affected. There are two chances in four that a child's genes will make him or her a carrier, but he or she will

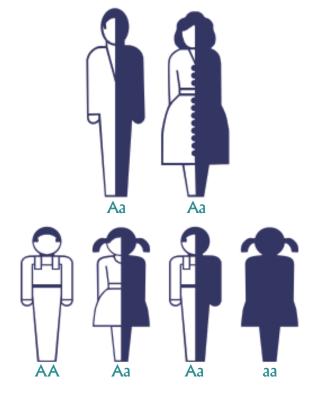
be disease-free. There is one chance in four a child will have two copies of normal allele and could never even pass on the problematic allele to his or her offspring. Recall that this statistical chance is repeated with the conception of each child.

About Medical Technology

On the question about how genetic tests are used and whether they are neutral, it is important to consider how specialists in this field regard them. Dr. Robert Lebel, a medical geneticist writing in an Evangelical Lutheran Church in America (ELCA) publication, notes the following: "We should combat the naive assumption that these testing methods are useful only for identifying pregnancies to be targeted for termination [abortion]. Such an assumption is a grave error because it overlooks the opportunity some families appreciate—to prepare themselves psychologically, financially, spiritually, and socially for the birth of a child with a handicap. In some few instances, it also allows for specific prenatal therapeutic efforts to be undertaken. In severe conditions, with survival impossible, it may provide the basis for "do not resuscitate" plans when delivery occurs."3

Moral and Theological Considerations

In considering where they stand on these issues, Christians will include the facts and perspectives of science and medicine, but will also look to resources in their faith traditions. Several relevant aspects will be sketched here: what factors to consider, guidance on the question of abortion, and the challenge to practice Christian friendship.



Factors for Decision Making

Dr. Lebel, now wearing the hat of an ethicist, reminds patients and caregivers of the many complex factors to consider in discerning wise decisions in these matters. His list for families to consider includes:

a) the strengths and weaknesses of the individual and the couple to meet foreseeable challenges, b) the family's financial resources, c) the impact on existing children, d) the benefits and burdens predictable in future children, e) the impact on society, f) the impact on the future gene pool, and g) the meaning of reproduction in the broad context of God's activity. These considerations will need to be given varying

weights, but all are important in attempting to discern God's loving intention for the situation. To ignore any of these is to miss an aspect of the big picture.

Lebel recognizes that such a list poses a rigorous challenge. He believes, however, that Christians are called to strenuously seek to be guided by the Christ-like principles of sacrifice, creativity, and generosity. He notes that in each specific case, the most creative option will not necessarily be obvious or easily discerned. But he believes such a rigorous effort can help move Christians toward faithful decisions and that grace can empower such full and careful moral consideration.

Contrasting Perspectives on Aborting the Severely III

The ELCA has provided guidance on the thorny question of abortion in "The Social Statement on Abortion" adopted by the Churchwide Assembly in 1991. Among other things the statement designates several pertinent convictions that include the following:⁵

"The act of intentionally terminating a developing life in the womb is an issue about which members of the Evangelical Lutheran Church in America have serious differences.

"All human beings, created in God's image, have intrinsic value and dignity and are to be treated with respect.

"As such, there is, therefore, a strong Christian presumption to preserve and protect life.

"Yet, there may be compelling circumstances wherein abortion may be an option of last resort, yet seen always as a tragic option. What is determined to be a morally responsible decision to abort in one situation may not be in another.

"In circumstances of extreme fetal abnormality, which will result in severe suffering and very early death of an infant . . . the parents(s) may responsibly choose to terminate the pregnancy."

The statement does not detail what constitutes "compelling circumstances" or "severe suffering." It does not engage in discussion of criteria about when personhood begins *in utero*, etc. It clearly has a preference for protecting life, but allows that exceptions do exist. While it gives guidance, it does not prescribe exactly what a couple like Allen and Sarah should do in their situation.

One Lutheran thinker, Hans Tiefel, is sympathetic to the reasons for the ELCA position, but respectfully disagrees. He asks whether it could ever be loving to abort a seriously ill pre-born, and concludes that it could not. As he writes: "I conclude that our faith may require more of us in the context of genetic testing than we are inclined to believe or accept. Our traditional responsibilities to the dying, our including the afflicted unborn in the community of faith . . . our commitment to God's will over our own (a God who does not explain our misery, but shares it) . . . all seem to point us toward keeping company with the dying child until their condition brings death."

Tiefel recognizes that this view is painful, and possibly cruel for parents of genetically affected children. The medical costs and emotional burdens can seem like more than flesh and blood can bear. Nevertheless, he argues that love may well require this of both parents and the church community. He notes that invoking the help of God and the body of Christ is an indispensable necessity in such a situation. He would argue that Allen and Sarah should not have to bear their burden alone.

The Challenge of Christian Friendship

Many dilemmas that result from genetic knowledge will not involve such extreme difficulties as Edwards Syndrome, but in all cases, they will raise the challenge of Christian friendship. Theologian Philip Hefner, has written about this idea in relation to genetic matters, and defines it in this way: "By this 'friendship,' I refer to the challenge to every Christian to offer respect, care, and support to Christian brothers and sisters who face the difficulties and traumas that come with genetic medicine—even when one disagrees sharply with the brother or sister, or even when the brother or sister has chosen a mistaken path."

Hefner believes the Lutheran insistence that none are justified except by God's grace through faith is the basis for such a concept and practice. This view recognizes several things. It recognizes that hard decisions must be made, that life is ambiguous, that sin is prevalent in all human actions, and that God has given his people a community to live in—the church. He acknowledges that this form of Christian friendship is a tremendous challenge. This is partially the case because persons with genetically related problems, like Allen and Sarah, are often reluctant to share their burdens with their local religious communities. The

reasons given often stem from fear. Couples like Allen and Sarah fear that their burdens are too great, too ambiguous, or too disagreeable for their friends to bear. They fear that disclosure will weaken their ties with the community of the congregation, and so they hide their situation from the friends who are most important to them.⁸

Clearly, when issues are as emotionally charged as in some cases involving genetics, it may be especially difficult to turn this concept of friendship into acts of care. Yet Hefner suggests that it is perhaps here—in communities of care for those whose lives have been marked by such ambiguities and disappointments—that we find the major challenge of genetic testing. As he concludes: "There is no greater treasure in the church today, however, than the possibility for Christian friendship... God has given no greater gift of grace than the love that can sustain such friendship."

A Common Theme

While the four sets of thought offered in this section may respectfully differ at certain points, a common theme does emerge. All agree that Christians are called to make decisions by criteria richer than the prevailing cultural idea of rights and self-fulfillment. All challenge the idea that each couple should simply choose in isolation to do what is "fulfilling for us." A society may consider "the right to do as I choose" as an adequate moral criterion in medical situations, but such reasoning is not adequate for Christian thinking. Couples are the ones to make their own decisions, but they are called to factor into their thinking both the community as the broader context for making their decisions and the criteria of Christ-like love. In so doing, they will seek to discern God's loving intention. Thinking beyond rights and individual choice may even be counter-cultural, but could this be what it means to be Christian in a society practicing genetic testing and screening?

Deliberation

As an exercise in moral imagination, answer the question: What would I do if I were in Allen and Sarah's situation? Why?

It is absolutely true that no one will ever know exactly what he or she would do in a situation until actually in it. However, imagining oneself in a situation is one excellent way to extend moral understanding. Such an exercise offers a means to move beyond just thinking abstractly about ideas. Therefore, take up the challenge to determine what you would do. Try to determine the factors to consider in making such a decision. What moral criteria would be important? Recall that although different means may be used to obtain an answer, the central moral question for Christians is: What is the godly decision in this case? One term for approaching a godly decision is called "discernment." One other way, then, to ask the question is: "What is your discernment in this situation?" Bring the input from above into this discernment. Bring additional insights available from personal experience into the reflection. Bring both humility and openness into this exercise.

Taking the Conversation With You

In order to take the conversation beyond the thinking stage, consider what actions might be possible for you or your study group. One way to consider this is to ask the following questions and then act upon them: What would Christian friendship mean in my congregation? What actions might it entail: Toward families whose children have a congenital condition? Toward the unborn with a congenital condition? Toward a couple who has chosen to have an abortion in such a situation? With some answers to these in mind, you might consider speaking with you pastor and reflecting together about how your congregation could further Christian friendship.

For Further Investigation

Committee on Medical Ethics, Episcopal Diocese of Washington. Wrestling With the Future Our Genes and Our Choices. Harrisburg, Pennsylvania Morehouse, Publishing, 1998. This book is designed to provide guidance for those within the Anglican tradition who are faced with decisions about genetic testing. The contents often overlap with the ELCA volume, Genetic Testing and Screening: Critical Engagement at the Intersection of Faith and Science, but give less attention to the broad social issues and theological questions that genetic testing poses. Its narrower focus, however, as a guide to making biomedical decisions offers richer reflection on those specific dilemmas.

Evangelical Lutheran Church in America, A Social Statement on Abortion. (1991)

Willer, Roger A., Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science (Kirk House Publishers, Minneapolis, 1998). Further investigation of the ideas above may be pursued especially in the chapters written by Philip Hefner, Robert R. Lebel, and Hans Tiefel.

Citations

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- **2.** Ted Peters, "Love and Dignity: Against Children Becoming Commodities." *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, ed. Roger A. Willer. (Minneapolis: Kirk House Publishers, 1998), 119.
- **3.** Robert R. Lebel, "A Geneticist's Synthesis: Evolution, Faith, and Decision Making." *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, ed. Roger A. Willer. (Minneapolis: Kirk House Publishers, 1998), 161.
- 4. Ibid., 160.
- 5. Evangelical Lutheran Church in America, A Social Statement on Abortion (1991), 2f.
- **6.** Hans O. Tiefel, "Individualism Vs. Faith: Genetic Ethics in Contrasting Perspectives." *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, ed. Roger A. Willer. (Minneapolis: Kirk House Publishers, 1998), 147.
- 7. Philip Hefner, "The Genetic "Fix": Challenge to Christian Faith and Community." *Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science*, ed. Roger A. Willer. (Minneapolis: Kirk House Publishers, 1998), 92.
- **8.** *Ibid*.
- **9.** *Ibid*.



Chapter Four—Genes and Human Behavior

"In popular culture, Elvis Presley has become a genetic construct, driven by his genes to his unlikely destiny. In a 1985 biography, for example, Elaine Dundy attributed Presley's success to the genetic characteristics of his mother's multiethnic family: "Genetically speaking," she wrote, "what produced Elvis was quite a mixture." To his "French Norman blood was added Scots-Irish blood," as well as "the Indian strain supplying the mystery and the Jewish strain supplying spectacular showmanship."

"Another Elvis biographer, Albert Goldman, focused on his subject's "bad" genes, describing him as "the victim of a fatal hereditary disposition. . . ." Goldman attributed Elvis's character to ancestors who constituted "a distinctive breed of southern yeomanry" commonly known as hillbillies. A genealogy research organization, Goldman said, had traced Presley's lineage back nine generations to a nineteenth-century "coward, deserter and bigamist." In Goldman's narrative, this genetic heritage explained Elvis's downfall: his addiction to drugs and alcohol, his emotional disorders, and his premature death were all in his genes. His fate was a readout of his DNA."

Introduction

These examples from Elvis' biographers may be unabashedly stereotypic and deterministic, but they illustrate how references to genetics have become commonplace. Genetic knowledge is increasingly used, and misused, to explain human behavior, and it is impossible to ignore its impact upon our understanding of human nature. The nature of the connection between genes and human behavior will remain controversial because the research is relatively new and involves flash points about personality traits, gender differences, intelligence, sexual orientation, and others. Yet, at the very least, the new genetic knowledge presses our society to confront the meaning of statements like "genes made her like that." It prods dearly held personal and theological beliefs about the character of human nature. It raises questions about responsibility and freedom. It demands our attention.

This chapter will help you explore this controversial subject. After completing it, you should have a better grasp of the science involved in questions about genes and behavior. You should gain, along the way, a new appreciation for how scientific developments impact theological ideas. You should be able to spot instances of genetic essentialism or determinism (the gene myth) that continually pop up in our culture. Finally, the chapter intends to acquaint you with several theological resources that respond to these challenging topics. These resources are part of what is called theological anthropology; that is, the understanding of the human person from a standpoint of faith.

Several significant questions serve as threads for this chapter. The primary one asks: What role do genes play in behavior? This question inevitably raises the long-standing nature vs. nurture debate in a renewed way. Is nature (genes) or nurture (upbringing and environment) the most significant factor in shaping human behavior? Related questions include: a) Are we really determined by our genes, and b) Are my genes the true "me?" Theologically, we must ask what it means when the study of genes uncovers inherited predispositions to adverse social behavior patterns—or to favorable ones. Each of these questions rubs up against an ancient and key Christian concept called the image dei (a Latin term meaning the image of God, see Genesis 1:26). What is the relation of genes to the image of God in us? Keep these in mind as you explore the rest of this chapter.

Personal Experience and Values

Each person brings to controversial topics some "pre-understandings." (As described in earlier chapters, this term indicates preexisting views based on experience and upbringing.) Take a moment to unearth some of your pre-understandings by reflecting on these questions.



The first is: What are your present ideas about the relationship of genes and human behavior? Do you hold the view, a fairly common one, that a human being at birth is a "blank tablet" and is therefore almost exclusively shaped by nurture (parents or others)? Or do you believe the opposite view, another common idea, that it is mostly "in the genes?" If you think both nature and nurture are involved, then what is the character of their relationship and interaction?

The second matter to consider is the term self? What is the essence of being a "self"? The term myself is often used without much reflection about what it means. What is it that makes you, you? What aspects about your identity could you not change without changing what is the truest you? Is it your physical features? Is it your genes? Is it your capacity to think? Is it your capacity to relate to others? Is it your personal history? These questions become important when thinking about the relation of genes and behavior.

Gathering Input

Science

Behavioral genetics (see sidebar) relies on several kinds of research to explore the influence of genes on behavior. The following examples provide a general familiarity with this genetic research. The first kind of research involves human twin studies,

in which identical twins who were permanently separated soon after birth, are studied over an extended period of their lives. Since these twins share an identical genome, research proceeds by comparing the differences and similarities in these individuals. Differences are considered largely the result of environmental factors. Another means of research involves the comparison of behavior profiles with the presence or absence of genetic material, such as that known to code for the production of dopamine (a neurotransmitter). Scientists also use "nature-nurture" experiments with generations of animals that are selectively bred for particular traits, and are then closely monitored in different settings. Much of this research is still

relatively new and such scientific research is characteristically contested and incomplete. Still, it seems to support several general conclusions.

First, scientists do not consider genes as the "cause" of specific choices made by any individual. Rather, genetic research explores the influence of genes on human temperaments (long-term manners of thinking, behaving, or reacting that are characteristic of individuals) that impact choices. Novelty seeking, social boldness, anxiety, and aggressiveness are examples of such temperaments. The research suggests that casual correlation (one to one) does not exist, but statistically significant correlation does. One summary of multiple studies of thousands of identical twins (raised separately), for instance, found that the inherited characteristics of assertiveness, altruism, extroversion, or introversion indicate a correlation range of 39 to 58 percent.² Measures of inheritable intelligence factors run around 50 percent.

Behavioral Genetics

Behavioral genetics is a relatively new branch of inquiry that investigates the relationship of genes and behavior. It seeks to determine the causative influence of genes on behavior and to generalize these findings. Behavioral geneticists, for instance, have conducted experiments to determine whether differences in the gene that codes for dopamine (a chemical in the brain) correlate with individual differences in novelty seeking temperament.

About the Categories

The meaning of terms in this scheme is as follows: Passive: the environment and the genes are provided by the same forces (that is, parents); thus, most early verbal learning is of a "passive" type.

Reactive: the genotype elicits different types of responses from social and physical environments that are not necessarily a matter of heredity; for instance, a "smiley" child tends to bring out the smiles in others around them.

Active: the individual seeks out environments compatible with or supportive of one's genetic potential; this is the most direct expression of genotypic influence on individual experience.3

Secondly, the relation of gene interaction with the environment remains difficult to pin down, but it is possible to classify certain relationships. One standard way, for instance, categorizes the gene and environment interaction in a threefold manner: a) passive, b) reactive, and c) active. Each of these has a very specific meaning in this scheme (See the sidebar) and most behavioral geneticists would caution that these categories, though conceptually necessary, must be understood as approximate and porous.

Finally, some of the most intriguing recent evidence suggests that the treatment of a child by parents and others in the early environment can clearly influence which genes are "turned on." Recall that the activation or suppression (being turned on) of certain genes is a fundamental mechanism of genetic activity. Skin cells become what they are because only the appropriate genes for making skin cells (from the entire set carried in every cell) are activated by physical mechanisms. In a similar way, genes that influence behavior often seem to be activated or suppressed by environmental influences.

What lessons can we safely summarize from this brief exploration of behavioral genetics? The primary one is that genotype *underdetermines* phenotype. This pithy summary indicates that a person's genetic inheritance (genotype) plays a recognizable role, but does not determine the observable consequences (phenotype). The recognizable role of genes means that a child cannot literally be any kind of person that a parent wants him or her to be. The belief that parenting and social environment alone shape personality does not fit with recent evidence.

Yet the evidence does not support the opposite notion that genes are one's fate. Predispositions do exist, but they do not predetermine. The complex interaction of gene and environment, in fact, seems to be a two-way street. Again, this is a recent claim, but one championed by numerous researchers. Just as the genotype gives significant direction to an individual's development, the environment, in turn, gives significant direction to the genotype. If true, this means the genetic predisposition to a temperament like *shyness* will be shaped by the interactions a child has with the important people in his or her life. A child with a strong predisposition to *novelty seeking* will certainly push on the boundaries in any setting. The outcome, however, will more likely be socially positive in an environment with constructive opportunities than in one dominated by destructive ones (for example, poverty and discrimination). In short, rather than determining one's fate, the research suggest that the genetic basis of behavior increases environment's importance.⁵

Theological Considerations

Conclusions drawn from scientific data, while crucial, cannot answer the tough questions about genes and human behavior. Moral and theological reflection on the issues of personhood, moral responsibility, sin, and others require a different kind of investigation. Such thinking should take the measure of scientific input, but involves careful interpretation and discernment.

Much of the confusion about the relation between genes and behavior can be laid at the door of what may be called the *gene myth* (any notion that "it's all in the genes"). The gene myth is a mindset that reduces everything significant about being human to the genes. We can identify two forms of this myth that often overlap. The first is *genetic determinism*. The scientific research above has largely responded to that notion. The other form is often called *genetic essentialism*. This is the idea, explicit or implicit, that whatever is essentially human can be reduced to the genes.

The Nature of Personhood

Simplistic media coverage contributes to the gene myth. So does the error of *reductionism*, which is more difficult to spot because it also appears in scientific contexts. Scientists must necessarily reduce complex phenomena into simpler pieces for purposes of investigation. For this reason, researchers necessarily look at the genetic code in isolation. Errors, however, follow when researchers (or others) transfer this necessary reductionism of scientific method into an interpretation of the human being. It is an interpretation that reduces the *essential* person to his or her genetic material. Such statements are common. Prominent geneticist Walter Gilbert begins public lectures with a compact disk of a gene sequence in hand, telling the audience: "Here is a human being; it's me." James Watson, co-discoverer of the double helix and Nobel Prize winner, has 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." At best, such statements leave a reductionistic impression.

At their worst, as social ethicist Elizabeth Bettenhausen notes, such statements play into a dangerous social mindset. "For many people," she writes, "DNA has taken on the social and cultural functions of the soul. It is the essential entity—the location of the true self—in the narratives of biological determinism. Perfect DNA is salvation." We might term this problematic view *personhood-in-the-genes*. Bettenhausen believes it is as dangerous as other attempts to determine the value of a person by reducing personhood to any single factor, such as skin color. Any such interpretation endangers a person's human integrity and social dignity. It also insults divine creativity.



In contrast to these views, Bettenhausen advances the notion of personhood as "a matter of living reciprocally in the presence of God, of oneself, of other persons, and of all creation. . . . " We might term this contrasting view *personhood-in-relationship*. This definition of personhood is one she finds rooted in Scripture and developed in the writings of Martin Luther. In this view, personhood is not identifiable with any single factor of the human being. Instead, it is described properly only by a reciprocity involving the individual, the community, and God. Only from this interaction is the human being given a genuine identity as a person. This view can incorporate the part played by the genetic code, but that sequence can never be the essence of the person. This is a powerful counter-message to an individualistic society that often falls into the reductionistic trap.

Responsibility

Theologian Ted Peters also challenges the gene myth because he is concerned about the issue of responsibility. This issue has two interrelated forms—legal and moral. He approaches the aspect of legal accountability by asking whether a genetic predisposition to antisocial behavior should make a person guilty or innocent before the law. He points out, as we have seen, that scientific research cannot prove a direct causal link between a person's genes and specific behavior. Correlation is not cause. Nevertheless, sometimes the gene myth is used to justify the judgment that genetic predispositions equals a compulsion to act. He points out that, if accepted, this view means society would have to choose legally between either setting free or social isolation. The first choice would jeopardize the welfare of others, while the second would violate individual rights.¹⁰

Peters seems to suggest that Christian thinking about this legal dilemma should take a clue from how most courts have handled cases of the *genetic defense*. The courts, with some notable exceptions, have held that a genetic predisposition does not eliminate the free choice to control it. The genetic predisposition has been accepted as a mitigating factor in sentencing, but not as a determinative factor in obtaining a verdict.

When he turns to the question of moral responsibility, Peters critiques the line of thinking that we might term *if natural, then acceptable*. This is yet another example of the gene myth, and he critiques it on two counts: a) it leads to logical contradiction, and b) it does not square with Christian insights. In this line of reasoning, moral right is determined by whether something is natural (natural here means "physically given"). In this case, the genetic predisposition is the "given," and this line of thinking holds that if a certain kind of behavior is established (as a scientific fact) to be in the genes, then that behavior must be morally acceptable, or at least excusable. Peters points out the logical fault line of this belief by indicating the contradictions to which it leads. For instance, if gay bashing and homophobia, as well as homosexuality were found to be "in the genes" and were therefore natural, would both then be equally moral? (He uses this example in light of scientific claims that certain forms of male homosexuality result from genetic predispositions. Whether or not these claims are validated does not change the larger point.) Obviously not, but this line of reasoning leads inevitably to this contradiction. The point is that scientific fact does not itself determine the moral interpretation of that fact.

This point is reinforced on Christian grounds in the nearly forgotten doctrine of original sin. An adequate exploration of this doctrine is not possible in these pages, but its central theme is straightforward. The doctrine's theme is the recognition that things are corrupted, not necessarily but inevitably, by sin and are not the way God intends for them to be. This central theme, at the very least, means that there is a certain distance between God's intention for what should happen in creation and what may be physically given in the genes. This theme implies that the morally good should not be determined by the leading of biology but rather by the loving intention of God. As Peters writes, "This theological tradition will be skeptical of arguments that seek moral approval on the basis of genetic determinism. The gene myth has no automatic theological endorsement. To reiterate: the scientific fact does not itself determine the direction of the ethical interpretation of that fact." In short, the Christian must look beyond the biology of a genetic predisposition to settle any question of what behavior is morally acceptable.

The Image of God

This search for determining the morally good will point the Christian to Jesus Christ. Christian teaching holds that genuine selfhood and the morally good are defined in him. Jesus' genome was completely human, and yet his life was the full expression of the IMAGE OF GOD (the *imago dei*). The human race finds its true definition in him. It finds its genuine identity and its salvation from original sin in God's life and work in him. The Christian points to Christ as the response to statements about the human genome as the essence of human nature. Christ, not the human genome as isolated by the Human Genome Project, is the prototype of a true human being.

We could say that these Christian views about personhood, moral responsibility, sin, and the selfhood move the nature-nurture controversy around genetics into a new and fuller key. They respond to the gene myth in our culture with a dramatic redirection of the discussion. Human behavior is indeed rooted in our genetic substratum, but the human person results from an awesome combination of heredity and environment within the handiwork of God. This identity is a gift emerging from the activity of the creating, redeeming, and sustaining God known in Jesus Christ.

Deliberation

"I always knew that something was wrong with me,' Glenda Sue Caldwell told reporters. 'I was not responsible for what I did. I'm a good person.' As her son, Freeman, walked through the front door of their Georgia home, Caldwell shot and killed him. She also shot at her daughter, who was sleeping in bed. The daughter lived. Convicted of murder and assault in 1986, Caldwell was sent to prison.

"By 1994, she was out of prison because Superior Court Judge Kenneth Kilpatrick granted her a new trial and found her innocent by reason of insanity. On what grounds? Caldwell has Huntington's Disease [see glossary], a genetic disorder afflicting 25,000 Americans. Some Huntington's sufferers exhibit the symptoms of depression and a growing predisposition to violent behavior. Judge Kilpatrick seems to have reasoned that if one is born with the Huntington's gene, and if it predisposes a person to violent behavior, then this constitutes innocence in the eyes of the law. He reasoned Glenda's case was one of diminished mental capacity due to genetic disorder." ¹³

Reflect on Glenda's case, using the input sketched above. Use the relevant scientific information and the theological considerations employed by the Christian thinkers. The questions to consider here include: What would you say to someone who agrees with Glenda Sue Caldwell that her genetic disorder made her innocent? What legal judgment should be made? What moral judgment about responsibility? What theological judgment about her status before God?

Taking the Conversation With You

Armed with the examples of the gene myth in this chapter, the reader might examine current media reports about genetics. In doing so, look for examples of genetic determinism or genetic essentialism. In what ways are these statements reductionistic? How might these examples influence thinking in our society? How might a congregation play a role in countering the gene myth?

For Further Investigation

Peters, Ted. *Playing God? Genetic Determinism and Human Freedom*. (Routledge, New York, 1997). This text examines the concept of genetic determinism from several perspectives, many that develop the ideas above. Peters' goal is to uncover concerns regarding human nature while building a theology of freedom and moral responsibility that is fully conversant with the science of genetics.

Willer, Roger A., ed. Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science. (Kirk House Publishers, Minneapolis, 1998). Themes about personal identities appear in several chapters, but the most direct thread is found in the chapter by Elizabeth Bettenhausen.

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Chapter Five—Gene Patenting?

The lead story on the front page of *The New York Times* of May 13, 1995, featured a headline reading: "Religious Leaders Prepare to Fight Patents on Genes." The contents of the story, based on press leaks, described efforts of a broad religious and secular coalition to initiate a nationwide educational campaign in churches, synagogues, mosques, and temples to raise awareness of and an outcry against the patenting of genetic information. The story portrayed the events as a "passionate new battle over religion and science."

The Rev. Herbert W. Chilstrom, presiding bishop of the Evangelical Lutheran Church in America at that time, was among many religious leaders who received from organizers of this campaign an invitation to become a signatory to a statement called the Joint Appeal Against Human and Animal Patenting. Although Bishop Chilstrom did not sign, 180 religious leaders did go on record in support of the following statement released at a May 18, 1995, press conference:

"We, the undersigned religious leaders, oppose the patenting of human and animal life forms. We are disturbed by the U.S. Patent Office's recent decision to patent human body parts and several genetically engineered animals. We believe that humans and animals are creations of God, not humans, and as such should not be patented as human inventions."²

Noteworthy

In order to avoid false impressions from a brief description of these events, we should note that religious leaders at the press conference were careful to affirm their support for the biotechnology industry insofar as it seeks to aid human well-being. They also indicated support, in principle, for the legitimacy of the industry's concern to make a profit. It is noteworthy that scientific voices, for example, the Council for Responsible Genetics, have also been raised in protest of current patenting practices.

Additional statements at the press conference warned that "Marketing human life is a form of genetic slavery," and "By turning life into patented inventions the government drains life of its intrinsic nature and sacred value. . . ."³

While many religious leaders obviously supported the campaign described above, others countered that the campaign was a well-intentioned effort misconceived. As one writer put it: "During the weeks leading up to May 18, 1995, well-intentioned religious leaders prematurely jumped into water over their heads. While thinking they had a lifeguard watching over them, they were in fact being dragged out to rough seas." The result, in this view, was a loss of precious credibility with those in the scientific, medical, legal, and commercial communities.

Introduction

The information above illustrates both the conflicts around the patenting of genetic information and the problems faced by people of faith who want to enter into the ongoing debate. On the one hand, the Joint Appeal initiated some limited, if indecisive, interaction with the legal and biotechnology communities around the issues. On the other hand, it has been critiqued from several quarters as having done more harm than good. Despite these mixed reviews and the campaign's questionable results (a national campaign never materialized) the Joint Appeal clearly hit upon sensitive nerves and key issues. Whatever one's final judgment, the event can be instructive and suggests the crucial importance of being well informed. Thus, it can serve the reader as a helpful touchstone.

In order to provide some insight into these important challenges, this chapter seeks to offer information and sketch views on the issues of patent law and genetics from several vantage points. These include perspectives from the legal, biotech, and scientific communities. Some commentators suggest that patenting issues ought to be settled solely on economic or legal grounds, but religious voices insist that humanitarian concerns must also be factored in. Several of these will be explored. The aim is not so much to draw even provisional conclusions as it is to gain a working knowledge of perspectives and concerns in the debate.

GENETICS!
Where Do We Stand as Christians?

Personal Experience and Values

Differing personal convictions and experiences about the question of the natural and the artificial underlie much of this debate. Take a moment to reflect on this question: What status does nature have in relation to human activity? When humans alter nature, how does its status change? Are natural events the "acts of God?" What does that mean? Can events involving human activity be acts of God?

The second pre-understanding important to this chapter concerns business practices and the public good. Consider: At what point should normal business practice be modified for the sake of the common good? What are the criteria? Have you ever personally experienced being treated as a commodity?

Gathering Input

Multiple Perspectives

Gene patenting is complicated because it entails information and values involving at least four different spheres: law, economics, science, and religion. This section will categorize the issues and introduce the legal background. It will then sketch the concerns of these multiple communities.

General Categories

Ultimately, the heart of the gene patenting controversy is the question: What is the status of the genome (especially the human one) and its components? Is it merely a chemical compound? Is it sacred? How is it intertwined with human (or other species) identity? The issues in the public arena, however, can be categorized under the following five headings:

- 1. Should there be patents on human DNA sequences and other living things that occur in nature, even if they have been altered through human invention?
- 2. What counts as natural and what counts as genetically altered?
- 3. What is the justification for granting patents on DNA material that is part of humanity's common heritage?
- 4. Does patenting human DNA sequences deny the dignity of human beings and human life?
- 5. What about justice and the common good, insofar as patents put the poor, the ill, and developing nations at a significant disadvantage?

The Legal Background

A patent is a form of intellectual property rights granted to an invention by The United States Patent and Trademark Office (PTO) if it meets three legally established criteria: 1) novelty; 2) utility; and 3) non-obviousness. (See sidebar for explanation.) Until 1980, legal interpretation had denied the eligibility of all life forms for patent rights because their discovery was considered akin to the discovery of an unknown river or a hidden valley. They were products of nature rather than human invention, and did not meet the three criteria. This was known as the Douglas Principle.⁶

Significance

The significance of this debate should not be underestimated. In 1999, the U.S. Patent Office granted some 1,800 patents for complete—but modified—genes of humans, animals, and plants. Approximately 7,000 others were being processed. Further, the negative impact of U.S. patenting practice on health care is already evident in the dozens of clinical diagnostic laboratories around the United States that have curtailed the use of certain genetic tests due to high cost or patent barriers. A prominent instance involves the Jewish community of Brooklyn, New York. The international program based there, which screens Jewish couples for potentially deadly Tay-Sachs, has been curtailed because the patent holder of a disease gene is trying to impose licensing fees.⁵

Novel means that an invention must have been previously unknown and unavailable to the public when a patent is filed.

Utility means an invention must serve a specific function or purpose as a useful contribution to the public good.

Nonobviousness qualifies an invention as involving an insight not obvious to a person knowledgeable about the relevant subject matter.



In 1980, the Supreme Court issued a landmark 5-4 decision that altered PTO practice dramatically. In *Diamond vs. Chakrabarty*, the Court ruled that a genetically modified strain of bacteria, useful for oil spill cleanup, could be patented. The rationale for this decision centered on the ingenuity required to modify the bacteria. While acknowledging that life forms in their natural state are not patentable, the Court held that altered life forms (transformed from their natural state through human intervention) were patentable [because] "Congress intended that anything under the sun that is made by man be patentable subject matter." The Court justified its decision in part on the assumption that a lack of patent protection for genetically engineered organisms would slow down the pace of research and the advancing economy.

In 1987, the PTO extended this justification to an animal that does not occur naturally when the "Harvard oncomouse" was patented (1998) as an invention. (Genes of this mouse were altered for research purposes to be susceptible to breast cancer.) Developments tied to the Human Genome Project (HGP) have exerted great pressures for the patenting of human DNA. Thus, by 1998, the PTO reported granting some 1,500 of 5,000 gene patents to researchers and it expects tens of thousands more as the HGP moves into a phase centered on analyzing the function of DNA sequences.

More on Patents and Genes

Three categories of patenting may be to distinguished. All involve genetic manipulation but differ in intent, result, and consequence. The first is the patenting of *genetically altered life forms* (such as the oncomouse). The second concerns patents for DNA *sequences*, primarily human DNA, none of which are life forms. The third has to do with patenting *genetic processes* that involve growing organs and tissues, either in the laboratory or in an agricultural setting, such as pig livers for human transplantation.

Patenting controversies are complicated by ambiguities between two types of patents: **a)** process patents, granted for the process by which a gene is located; and **b)** composition patents, granted for the physical product derived from the process. The difficulty in distinguishing between the two can be illustrated by cDNA (copyDNA). Is obtaining cDNA a process by which a chemical structure is identified or is it a physical composition?

The debate is not whether genes as they exist in nature should be patented. It is agreed they should not. Rather, the debate involves whether genes that have been altered in some way may be protected by patent. The question is whether new forms of genes, those produced through human intervention, should be. The significant ambiguity here is what counts as human intervention. One example can help demonstrate this ambiguity. It revolves around whether cDNA (copies of expressed DNA material) are considered a natural product or a human invention. Patents for cDNA have been granted on the grounds that obtaining copies involves significant human ingenuity. Critics, however, point out that the information being patented is the *exact* sequence of a human gene as it exists on the genome. This view holds that such information is a common human heritage. Therefore the patenting of human cDNA means that the human genome will be owned, in effect, by a handful of companies or governments as intellectual property.

The Biotech Industry

In defending the practice of patenting DNA and life forms, biotech industry representatives have generally insisted on describing genes and DNA as strictly chemical compounds. The language of the

legal decisions regarding gene patenting reinforces this definition. The importance of such definitions should not be missed in attempting to sort out differences between the industry and its critics.

In line with this view about DNA, patenting is considered the guarantee necessary for the advancement of research and the development of products for the market. This logic is consistent with that of other branches of the biotech industry. John Varian, a biotech financial operating officer, writing in an ELCA publication, explains that any biotech development is a risky business decision for several reasons. He uses the example of a shoe store developer: "None of us would risk the time, money, and effort to develop a new sandal for our shoe store if those other ten stores could immediately copy it and sell it for less." Without proprietary position (patents), he suggests, firms fear that others would copy their developments and undercut profitability. Varian also points to the exceptionally high stakes involved in biotech business decisions since they involve huge initial investments and the high possibility of failure. Only patent protection will lure forth the necessary effort and venture capital. Many in the industry thus contend:

a) that only patents will guarantee the development of genetic products at all, and b) this debate impinges on its economic survival.



The Scientific Community and Patents

The scientific community is divided on the question of human gene patenting in regard to research, largely on two counts.

The first is an argument over whether patent applications for most DNA sequences are premature because they comprise gene fragments whose functions are largely unknown at the time and thus fail the utility criterion.

The second source of controversy involves whether patents encourage or discourage the development of research and knowledge. Some hold that gene patents obstruct the practice of shared discovery that makes science possible. Others insist that patent protection is necessary to provide the intellectual space to proceed with painstaking research. Yet another view is that the proliferation of gene patents creates too many overlapping fragments of intellectual property and too many owners. This fragmentation will create serious problems for future research and product development. In short, this view fears that the privatization of information will result in the under-utilization of knowledge, increased price, and restricted use.⁸

Theological Considerations

While the patenting dispute involves social, economic, and scientific concerns, religious voices have insisted that other concerns also must be heard since genetic patents involve human life and well-being. This section will first address the status of DNA theologically, and then sketch the issues of dignity and justice that religious voices have brought to the debate.

Creation and Patents

"We believe that humans and animals are creations of God, not of humans, and as such should not be patented as human inventions. This line from the Joint Appeal summarizes an objection to patenting that is often made. But some theologians have pointed out that such logic, even though used by people of faith, misstates the Christian understanding of creation and weakens the case against patenting.

Two points of the Christian doctrine of creation are important here. The first holds that God creates everything from nothing, and the second holds that God's creative activity is continuous and dynamic. God's creative activity is thus ongoing with every new moment and did not happen just once "back then."

These two convictions contradict any viewpoint that sharply divides creation into the natural and the artificial, and assigns God's creative activity to one, but not the other. These two convictions deny the implication that natural creatures somehow have a God-given dignity that artificial ones do not. In the doctrine of creation, the oncomouse is just as much a creature of God's creation as is a wilderness field mouse. Both have God-given dignity and both are equally gifts of God's creative activity. There is a distinction of means between the natural and the artificial, but every living being, whether genetically altered or not, issues from within the activity of God's creation. The premise here is that human ingenuity is a

natural gift of God and that at its deepest level, the artificial is also nature at work. In this sense, divine creativity works through human creativity.

It does not follow that every human decision about genetic alteration is consistent with God's loving intentions, but the doctrine of creation does set the proper framework. There may indeed be reasons not to patent DNA and genetically altered life forms, but such a decision should not be based on a faulty distinction about creation. We shall now turn to several of these arguments.

Dignity and Commodification

Many in the religious community contend that the God-given dignity of life is the basis on which to

What exactly is commodification?

A commodity is anything that someone is willing to sell or another is willing to buy. Commodification is the process by which something previously valued in non-economic terms (in this case, knowledge about genes) comes to be understood as a market commodity. A complaint about the commercialization of Christmas or Valentine's Day is about commodification, albeit a less profound issue.

challenge some forms of genetic patenting. This is a moral argument rather than a philosophical question about being natural. This challenge to patenting is often pursued under the heading of *commodification*. Again, a statement from the May 18, 1995 press conference may serve as a starting point. "The patenting of genes, the building blocks of life, tends to reduce it to its economic worth." ¹⁰

It is important to note that the charge of commodification in a narrow sense—the actual buying and selling of goods or services—is not the concern here. Patents on genetic material or genetically altered animals do not represent ownership of that life. Rather, they represent the right to ideas or information that may be developed for sale.

The concern of religious voices (and some non-religious as well) in this debate is about commodification in the broad sense of the term. These voices have argued that the God-given dignity of life forms—an inherent one—is degraded by subjecting fundamental information about them to monetary transaction. This occurs whether or not they are actually traded in the marketplace. Commodities are not accorded inherent dignity for what they are in themselves, but are valued only for what price they can bring or the uses to which they can be put. The fear about commodification in this broad sense is really a fear of encouraging a mindset that reduces everything to a one-dimensional economic value. This charge of commodification registers a clash of mindsets more than an objection that patents commodify genes in a narrow sense. The fear is that the patenting of life forms and of DNA will edge society closer to their abuse. For example, the concern is that we are moving toward a world in which a person's patented cell line (that of a sports star, for instance) would be valued rather than the person.

Justice

Besides commodification concerns, religious voices (as well as humanitarian ones) have raised concerns about justice. This concern results from the monopoly of power over products gained by holding patents. These voices insist this is an appropriate concern since these genetic products are predominantly medical in nature and beneficial to human health and well-being. Christian voices support this challenge to current patenting practice by pointing to the biblical message of God's special concern for the poor. This is buttressed by pointing to Christ's compassion for the ill and concern for "the least of these." These voices note that current practices increase medical costs for everyone. Such practices also penalize the ill who are poor or who live in developing countries with fragile economics. For these reasons, these voices argue that some exception to patenting and traditional market mechanisms should be sought out. They urge either that patents not be granted or that special economic arrangements be developed.

Conclusion

As promised in the introduction, we have only been able to suggest the competing perspectives at work in the patent dilemma. No resolution is attempted. Yet, Christian attention to the debate is important since practices being shaped today will likely have long-term impact. Religious voices do add a distinctive contribution if carefully and effectively exercised.

Deliberation

The following set of principles (a reduced version) for guiding religious voices in the patenting debate is taken from the work of theologian Ted Peters, who has written several times on these issues. He issued these recommendations specifically with the Joint Appeal controversy in mind. As an exercise in theological and moral deliberation, consider the usefulness of these for the patenting debate.

Religious voices should operate according to the following guidelines:

- Disregard the attempt to draw a connection between divine creation and a ban on patents as proposed by the Joint Appeal Against Human and Animal Patenting. There is no warrant for treating nature prior to human technological intervention as the sole domain of divine creation. Nature is not less sacred after being influenced by human ingenuity. Rather, pursue a theological vision that affirms continuity between humanity and the rest of nature, and affirms our divine call to be stewards. The goal of stewardship is to relieve suffering and make the world a better place.
- Avoid simplistic and misleading rhetoric that confuses the present controversy. In addition, seek increased precision regarding the term *gene patent*. If the word *gene* refers to what exists naturally in the human genome, then no patent should be issued. If gene refers to a copied sequence—that is, cDNA—that matches the original genome, then, likewise, no patent should be issued. If, however, *gene* refers to an altered or engineered DNA sequence that is novel, useful, and non-obvious, then intellec tual property protection should be considered.
- Take seriously the concern expressed by the Joint Appeal Against Human and Animal Patenting that the dignity and integrity of life be safeguarded. Affirm the enormous difference between a patented



cell line and a living human being, and remain alert to any reduction of the latter to the former. Ever present is the temptation to "thingify" or commodify. Develop guidelines so that animals and persons with genetically modified cells retain the dignity and integrity they deserve.

• Treat all living animals, even those genetically engineered, with a level of dignity that lifts them up above mere inanimate things. Encourage research practices to minimize suffering to the extent possible in each situation. Animals are not things, even if their genetic makeup results from a technological process.

Taking the Conversation Further

Ask someone in your group to investigate the current controversies involving genes and patents by researching the media or using the Web. Are religious voices involved? This report could be followed by an invitation to both sides of the controversy to speak to your group. In many communities, helpful resources for this include local members of the legal profession, biotechnology industry, or activist groups. If one is available, invite a theologian or ethicist as well.

For Further Investigation

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- **6.** So named for Justice Douglas, who held in a 1948 ruling (*Funk Brothers Seed Co. v. Kalo Inoculant Co.*) that "patents cannot issue for discovery of the phenomena of nature . . . [Such] are manifestation of laws of nature, free to all men and reserved exclusively to none."
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Chapter Six—Genetically Modified Organisms

"Genetically engineered potatoes and other crops already cover 45 million acres of American farmland. Biotechnology is agriculture's most carefully cultivated secret—and maybe the root of the next farm crisis."

"Joe Williams, a Virginia tobacco farmer, has been forced to cut his production nearly in half over the last three years as people have kicked the smoking habit. But he is hoping that a small experimental plot he just planted will hold the key to his staying on the farm. That tobacco has been genetically engineered to produce not cigarettes but pharmaceuticals.

Plants containing drugs could, indeed, represent a new high-priced crop. 'If we can actually find a medical use for tobacco that saves lives, what a turnaround for the much-maligned tobacco plant,' said Christopher Cook, chief executive of ToBio, a company recently formed by Virginia tobacco farmers like Mr. Williams to grow drugs in cooperation with the CropTech Corporation of Blacksburg, Va.

The production of drugs in genetically altered plants—called molecular farming or biopharming—seems poised to represent the next wave in agricultural biotechnology. . . . "2"

"Washington, D.C.—Six farmers are suing biotechnology giant Monsanto, claiming the company skipped safety tests in its rush to bring genetically engineered seeds to the marketplace. The lawsuit, handled by a cadre of powerful environmental and antitrust lawyers, also accuses Monsanto of conspiring to control the world market in corn and soybean seeds.

The class action lawsuit, filed in Federal District Court in Washington, D.C., is the latest attack on bioengineered seeds. The seeds proved so popular among American farmers that, by some estimates, up to one-third of U.S. cornfields were planted this year with genetically modified corn, and half the soybean fields held modified soybeans.

But those figures could drop dramatically next year, as farmers react to intense pressure from European consumers and environmentalists who say the crops could harm humans and the environment."³

Introduction

The introduction of *genetically modified organisms* (GMOs) in the early 1990s has been marked from the beginning with extensive controversy, as typified by this smattering of newspaper coverage. Proponents claim biotech developments herald the next agricultural revolution that promises the alleviation of a) mass

GMOs

For the purposes of this discussion, a *genetically modified organism* (GMO) refers to plants produced by inserting a sequence of foreign DNA into the nucleus of a recipient organism. The new DNA thus becomes part of the recipient's genome, and the now-modified recipient produces a totally new protein in the host. Genetically engineered foods represent a sub-category of GMOs since they are modified plants grown for direct human consumption.

starvation and global turmoil in the face of massive population growth, and b) environmental damage due to the overuse of pesticides and soil. Opponents argue that a) mass starvation results from inequitable distribution rather than inadequate food supply, b) sustainable agriculture is a much better alternative, c) GMOs may well be unsafe for human consumption, and d) high volume biotechnology risks numerous disasters to the global food system, the family farm, the environment, and the economy. Besides such social contentions, GMOs are prompting other unusual questions, such as: Could genetically modified food be kosher and is it suitable for Holy Communion?



The aggravated intensity of these debates is perhaps understandable since this technology affects the pillars of life: food supply and environment. As "bread and butter" matters, they affect everyone, even though farm communities and impoverished nations are most immediately aware of the problems. The complexities, then, are not simply about new forms of technology, but they involve human health, trade, the environment, global corporations, government regulation, the farm crisis, and the world food supply—just to name a few!

We can only begin to scratch the surface of such a multitude of issues, especially since very little has been written about them from a specifically theological standpoint. The goals of this chapter are, therefore, modest. It intends to give the reader a brief tour of several key aspects of this important controversy—a controversy that largely has lacked sustained public attention. In this way, the reader should be more prepared for the extended public debate that everyone—on all sides of the issues—agrees is needed.

GMO Packet

The ELCA's Rural Ministry Resources and Networking Office has prepared a *GMO Packet* that includes a variety of documents (non-theological) on this topic. It can be obtained by contacting the ELCA Rural desk (800-638-3522 ext. 6556, e-mail rural_web@elca.org, or online at www.elca.org/do/ruralhome.html).

Several key questions will guide this tour of GMOs.

What does "genetic modification" mean and how is it possible? What are some of the primary issues? How do these issues affect the average American citizen? How should these concerns be evaluated? What are some of the theological and moral principles useful for analyzing these issues? This chapter examines these matters and presents ideas for reflection and discussion.

Personal Experience and Values

Such bread-and-butter matters affect everyone at a deep level. Consider your pre-understandings on several of these matters before you begin to read. Are you comfortable with the idea of modifications to the foods you eat? Why or why not? How much modified food do you believe you currently ingest? How much assurance do you want that modifications are safe? Do you trust the adequacy of current regulatory practices?

As with many issues involving genetic engineering, corporate practices have become sources of controversy. Should bioag corporations be regulated or restrained more closely than other kinds of agricultural business? Why or why not? At what point do you believe that normal business practice should yield to public concerns? What are the criteria? Would you be willing to pay higher prices in the grocery store in order to compensate for the cost of greater regulation or less efficient production?

Gathering Input

Scientific Information

How exactly are GMOs created? The process is complicated and involves numerous steps. Yet, the key technological advancement, greatly simplified, is much like cutting and pasting a string of letters from one document into another. Technicians isolate a genetic sequence and "snip it" at both ends, using what is called a restriction enzyme. This removes a portion of the original DNA sequence from its chromosome and leaves several unmatched A- or -T, C- or -Gs "hanging." A "molecular glue" enzyme (Ligase, for example) is then used to splice a section of a foreign genetic sequence at the snipped site by matching it with the missing A-T and C-G bonds on both ends. A new sequence now exists, one with instructions for producing within a cell what was previously a foreign protein. If the engineered organism is a plant seed, the new protein becomes a feature of the plant as it grows since the new DNA sequence is duplicated every time the engineered cells replicate.

The B.t. potato offers an illustration. A portion of the DNA of a soil bacterium called Bacillus thuringiensis (B.t.) has been spliced successfully into the potato genome. In its natural environment, this bacterium is a naturally occurring insect killer considered harmless to humans and wildlife. B.t. has, in fact, been applied externally for many years as a biopesticide. With a part of its genetic code now spliced into the potato genome, it becomes internal to the plant. Whenever an insect nibbles the genetically modified plant, the bacterium's poison is produced in its belly, and the insect dies.

B.t. crops now include corn and cotton, and many others are being tested. There seems to be great promise, and yet, signs for caution. On the positive side, the uses of B.t. in these crops have definitely increased crop yield. However, documented cases of evolving resistance among targeted insect populations are now appearing. Further, the effects of B.t. plants sometimes seem not to be limited to target insect populations. For example, cases of high mortality rates for Monarch butterflies (discussed below) have been documented in the vicinity of B.t. fields.

Weighing the Pros and Cons

The arguments about GMOs can be broken down into five categories, and each with its own contested pros and cons. These are: food safety; environmental protection; consumer benefits; producer (farmers) benefits; and economic consequences. One common way to weigh a multitude of pros and cons is through risk versus benefit analysis. This kind of thinking compares how much benefit is gained against the significance of risk involved. Readers may gain a sense of the kind of arguments that need to be weighed from considering the partial review here of the first two on that list—food safety and environmental protection.⁵

Food Safety

Are GMO foods safe? Proponents of GMOs ask what harm has been demonstrated by GMO foods already on grocery shelves. In the United States, GMO crops were first commercially harvested in the mid-1990s and by the year 2000 nearly 55 percent of all soybeans, 35 percent of corn, and 50 percent of potato acreage hosted genetically modified crops. (The U.S. Department of Agriculture—USDA) has approved more than 50 genetically modified crop plants and dozens of others are being developed.) Roughly 60 to 75 percent of all processed foods on supermarket shelves now contain GMO ingredients. Proponents point out that no large-scale human health problems have been reported. Opponents counter that the degree of harm is actually unknown since many GMO products have been designated "substantially equivalent" (see

Existing U.S. law does not require GMOs to be labeled because the USDA has determined that they meet the twin requirements of U.S. regulation: substantial equivalence and familiarity. This dual designation means that GM foods are marketed like any other product because they are not substantially different from traditional products with which consumers are familiar.

A partial list of foods that tested positive for genetically modified ingredients in a 1999 study from the Center for Food Safety in Washington, D.C.: Aunt Jemima Pancake Mix • Ball Park Franks • Betty Crocker Bac-Os Bacon Flavor Bits • Bravos Tortilla Chips • Duncan Hines Cake Mix • Enfamil ProSobee Soy Formula • Gardenburger • General Mills Total Corn Flakes • Heinz 2 Baby Cereal • Jiffy Corn Muffin Mix • Kellogg's Corn Flakes • McDonald's McVeggie Burgers • Morningstar Farms Better 'n' Burgers • Nabisco Snackwell's Granola Bars • Nestle Carnation Alsoy Infant Formula • Old El Paso Taco Shells • Óvaltine Malt Powdered Beverage Mix • Ultra Slim Fast • Post Blueberry Morning Cereal • Quaker Chewy Granola Bars • Quaker Yellow Corn Meal • Quick Loaf Bread Mix • Similac Isomil Soy Formula⁶

sidebar) by the USDA. This designation means that no significant testing has been required and no monitoring is employed. The minimal data available concerning safety, therefore, comes from corporations that market the product. Opponents thus hold that the lack of known safety problems in genetically engineered food now on the market does not prove them safe.

Do genetically modified foods increase the risk of allergens in the food supply? The industry holds that the relatively few ingredients (such as peanut proteins) which account for 90 percent of all food allergies in humans should, of course, receive special review. All other ingredients, however, do not require such review or justify labeling. Opponents counter that, again, the absence so far of widespread problems does not prove that other engineered food products will or will not introduce allergens. All engineered ingredients, therefore, should require review. As evidence for the needed caution, they point to previous cases, such as one involving soybeans and Brazil nuts. Plans had been made to market, for animal feed, a soybean engineered to produce a nutritionally valuable amino acid. However, commercialization was cancelled after it was discovered that the protein produced by the gene was a Brazil nut allergen capable of causing severe reactions in humans.



Is labeling food the answer? Many urge that labeling is the solution to questions of safety and consumer worries since it would give consumers their choice. The industry is reluctant to label for fear of consumer misunderstanding and because of the complexities involved. They ask such questions as: What is to be labeled? What is the target of the label? What are the methods to determine the labeling? What is the threshold? How will international harmonization of labels be handled? What about the additional costs involved.

What is the nutritional benefit to consumers? In terms of risk versus benefit assessment, opponents ask whether GM foods actually benefit consumers. Are GM foods more nutritious or less costly? The industry agrees that the current answer is largely no. They believe, however, that this assessment will change in the near future and, therefore, no restrictions are justified now or in the future.

Environmental Protection

Proponents of "bioag" products argue that they will benefit the environment.¹⁰ They contend that modified seeds can encourage the use of environmentally friendly pesticides and even reduce pesticide use completely. For example, modified crops can allow farmers to plant with only one herbicide treatment and also eliminate the need for cultivation, retaining precious moisture in the soil and reducing erosion potential. Anticipated bio-applications will also increase fertilizer efficiency.

Opponents cite environmental difficulties. The dominate concern here is the creation of "super" weeds or pests in the target population. For example, when the herbicide Roundup was first introduced 15 years ago, it effectively killed every plant. Documented cases now exist of plant species building resistance and becoming largely unaffected by this herbicide. Secondly, there is concern about gene flow from an engineered plant species to wild, related species through cross pollination, although the scientific data are still being assessed. A third area of concern involves the impact of genetically engineered crops on non targeted insect populations. Critics here point to documented cases of harm to monarch butterflies and ladybugs. Finally, there are also concerns about long-term negative effects on biodiversity since the handful of already limited food crops will receive the greatest share of attention from this expensive technology.

Are there alternatives? Opponents believe that sustainable agriculture offers benefits similar to those proposed by biotech proponents, but without the risk. Further, they note that biotech practices effect nearby organic fields whenever GMO plants or herbicides are introduced into the local ecological system. Those in favor of biotechnology doubt that sustainable agriculture can be practiced on a large enough or successful enough scale to handle the looming reality of dramatic population growth.

Conclusion

Clearly there is much to ponder on both sides of GMO issues in trying to establish a risk versus benefit analysis. Beyond such calculations, though, Christians will want to factor in commitments from a faith perspective. We now turn to those convictions.

Theological Themes and Moral Guidelines

Christian thinking about GMOs, agribusiness, farming, and the food supply need to be framed by our understanding of the meaning of God's creation and the human role in it. Christian thought—and, indeed, western thought in general—has often pointed to key passages in Genesis as the basis for such understanding. Genesis 2:7 indicates the close relation between human beings and the earth by poetically pointing to humans as created from "the dust of the ground." Likewise, Genesis 1:26 records God giving dominion over his handiwork to the human creature. Such dominion has often been interpreted to mean that humans may do largely what they want. If so interpreted, few restraints on wholesale genetic modification would seem warranted.

Dominion as Stewardship

The ELCA social statement Caring for Creation: Vision, Hope and Justice insists upon a more careful and nuanced meaning of dominion.¹² It suggests that the biblical word "dominion" means to steward the earth, not exploit it. Humans are responsible for keeping God's "garden," the earth, just as God would. Further, this stewardship is to be modeled after Christ's servanthood (Philippians 2:7). The ELCA statement notes that science and technology can help us to discover how to live according to God's creative wisdom, but that they must be carried out in humility and in an awareness of the web of life for which humans are responsible. The social statement also states that human responsibility for creation has often been faulty or weak. It calls upon Christians to recognize that the environmental crisis is both a serious reality and is caused by sinful human practices. The statement ends with a proclamation of the hope for restoration of

all creation rooted in God's mercy. Such a biblical understanding does not present immediate answers to specific questions like whether we should use B.t. corn or not. Yet, it can guide thinking and does rule out certain convictions, such as the belief that actions may be guided by sheer profit motive or sole attention to human wants alone.

Guiding Principles

What these ideas mean in terms of biotechnology need to be worked out into more specific recommendations. Richard Crossman of the Evangelical Lutheran Church in Canada has done such thinking in a chapter of a report commissioned and published by the United Church of Canada. He delineates some policy guidelines helpful for specifying concerns in biotechnology matters.

The first is the acceptance of the *Precautionary Principle*. This principle was formalized at the 1992 United Nations Conference on Environment and Development as a guide for research and other biotechnology activity. It can be defined as the dictum "to act in such a way as to not make the planet a laboratory in a trial and error experiment." The primary point is that precaution should have the upper hand whenever questions of human or environmental health are involved. This principle counsels restraint until all cause and effect relationships are fully and safely established. Moreover, Crossman suggests that the parties proposing the activity, or those benefitting financially, must bear the burden of proof. This practice would reverse the current situation in which the burden falls largely upon the public to react to and deal with any negative consequences after they arise. He recognizes that such a cautious approach is contrary to much current research or business practice and may slow down or temporarily halt it. He emphasizes that Christian care for creation, however, justifies such caution and he notes signs of its implementation.¹⁵

His second guideline might be called the *Involvement Principle*. It insists that biotechnology projects require close monitoring and public accountability. Good decision making, he argues, can occur only when there is full knowledge of both the activities and their implications. As a result, public agencies should be encouraged and empowered to monitor not only safety concerns, but also the impact of the processes generated in bringing the product to market.

To accomplish all of this, he suggests that the following steps will need to be taken to:

- Support the labeling of genetically modified food.
- Give keen attention to monitoring economic and political activity regarding the development and approval of biotech processes and products (both short and long-range).
- Encourage public participation in and awareness of public debate on biotech concerns.
- Press government and corporations to pursue activities that benefit the whole of creation (including those who are marginalized) rather than only those activities that will generate a large profit.
- Press for a period of time in all biotech processes that gives space for ethical reflection as a part of any biotech development activity. This would be a requisite time in which research, education, and global monitoring would allow large numbers of people to understand the problems they face and offer them the means to [ethically] address these problems.¹⁶

Crossman argues that such steps are justified because large numbers of people are impacted by biotech activity. He recognizes the difficulties and likely resistance, but believes such steps are the only way to recover effective levels of moral impact in biotechnology decisions.

Deliberation

The following recommendations regarding biotechnology are selected from a set of remarks made by a respected authority on agriculture in the developing world. They were made to an agribusiness corporation's board of directors with the explicit purpose of encouraging responsible business practices that reduce environmental risk and encourage the acceptance of biotechnology (see sidebar on next page).

Evaluate these recommendations in light of the ideas presented in this chapter. Use moral imagination to think about what a Christian businessperson on such a board would need to think through. In this process, apply what you know about GMOs, risk-benefit analysis, and stewardship of creation principles. Where are these recommendations adequate or inadequate? What sort of board action might be needed in light of them?



Recommendations

- Seek corporate actions that are "doubly green;" that is, they are successful in productivity, but are also environmentally friendly.
- Advocate labeling as a response to food and environmental safety concerns. Support the notion that customers should have the choice of being informed whether or not they are eating GM foods.
- Develop and require extensive greenhouse and field testing for all GM plants before being released to farmers and the public. This would include supporting the establishment of effective national and international biosafety protocols and facilities.
- Add a broad concern for the well-being of the poorest as a goal shared by this company (with private and public agencies). This would entail seeking a balanced set of ground rules to ensure that everyone in the world can have the possibility of improving their lives and livelihoods. The justification is that the future of the poor is an important part of the context in which a company does business.

These recommendations are drawn from remarks made by Gordon Conway to the Monsanto Corporation Board in June of 1999. Conway was invited to address that group on behalf of the Rockefeller Foundation, which has devoted significant resources to biotechnology research in developing countries.

Conway is a noted authority and author of *The Doubly Green Revolution: Food for All in the Twenty-First Century*,¹⁷ a book on global food security. He is the former vice-chancellor of the University of Sussex.

Monsanto is a corporate leader in genetically modified agricultural products and has publicly argued for unfettered development of biotechnology. Their practices have also been at the center of several GMO controversies.

• Use a plant variety protection system in developing countries in cooperation with public breeding agencies, rather than using patents to protect crop lines. This system prevails in Europe and allows farmers to save seed for their own re-use. It also means plant breeders may use seeds in research designed to produce further improvement. These are advantageous for the common good.

Taking the Conversation With You

As always, an educational event in your congregation can help carry the conversation further. Arrange for a speaker or plan an additional study for your congregation on biotechnology issues. Most communities have local sources for speakers on this topic. These include local institutions of higher education, both religious and secular. Other sources include social action groups and businesses. These sources could provide scientific and technical knowledge or prompt moral and theological conversation.

For Further Investigation

Evangelical Lutheran Church in America, A Social Statement on Caring for Creation: Vision, Hope and Justice. 1991.

Commission on Christian Action, RCA. Genetic Engineering: An Update by the Commission on Christian Action. (Office of Social Witness, Reformed Church in America, New York, 1999). This pamphlet is written by a biologist and seminary professor and provides a brief look at "the very least we have to know about genetic engineering." It also features an excellent bibliography, including Web sites.

Taskforce on the Churches and Corporate Responsibility. Biotechnology & Genetic Engineering: Current Issues, Ethics, and Theological Reflections. Nancy Palardy, lead author and research associate. Etobiocoke, Ontario Canada. (Division of Mission in Canada, The United Church of Canada, Ontario, 2000). This small book represents an ecumenical effort to address biotechnology in an accessible way. It contains a significant emphasis on economic and social justice concerns. The first section provides a helpful introduction to genetic engineering (especially in its agricultural forms) that categorizes the issues, the economic players, and the nature of public debate.

Further information on this topic will also be found at:

<www.whybiotech.com/home.html>; < http://ccr.ucdavis.edu/biot/index.html>; and



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- **13.** Dr. Crossman's work is not based on the ELCA's statement *Caring for Creation*, but his principled concerns bear a sufficient family resemblance that permits this connection at the level of middle axioms.
- **14.** Richard Crossman, *Biotechnology and Genetic Engineering: Current Issues, Ethics, and Theological Reflections Taskforce on the Churches and Corporate Responsibility.* (Etobicocke, Ontario Canada: Division of Mission in Canada, The United Church of Canada, 2000), 58.
- 15. Ibid, 59.
- **16.** *Ibid*, 61.
- **17.** Gordon Conway, forward by Vernon W. Ruttan, *The Doubly Green Revolution: Food for All in the Twenty-First Century.* (Ithaca, New York: Cornell University Press, 1999.)



Chapter Seven—Genetics, Christians, and the Public Debate

"Time and again, particularly in the past thirty years, the United States has repeated a cycle. . . . Quite unexpectedly, or at least seemingly so to those who do not follow scientific developments, scientists announce a discovery. The media covers the story, albeit with as much sensationalism as possible. The public then responds to the announcement with surprise and consternation. A few ethicists and official religious bodies formulate positions, but often well after the controversy has passed. Eventually, most people cautiously accept the new technology, some because there seemingly is no choice and others because they overcome their initial negative reaction.

"[There are] . . . many such instances of this cycle of discovery, reaction, and cautious acceptance. Artificial insemination by donor, considered to be a form of adultery fifty years ago, has become a widely accepted practice in the treatment of infertility. Prenatal diagnosis (introduced in the late 1960s) and *in vitro* fertilization (first available in 1978) similarly evoked consternation and then general acceptance. When recombinant DNA research was initiated, scientists, as well as the public, had concerns about safety and the unintended release of genetically altered organisms into the environment."

Introduction

Does the cycle noted above indicate that our society will reluctantly, but relatively quickly, accept every biotech innovation that comes along? Will our culture in the near future practice all conceivable forms of genetic testing, genetic medicine, genetically modified farming, and human cloning? Could our society instead debate these matters and say "No" to a specific application of a technology? Could these debates include moral and religious concerns? Should the church as an institution be involved in these public conversations?

To effectively answer "yes" to any of these questions, Christians must think through how to call for and how to take part in a meaningful public discussion. There are several means for such activity. One significant avenue involves individual Christians, on the basis of their faith and knowledge, speaking out on the public questions that are just below the surface in many of the genetic developments explored in this study guide. Another way invites the congregation to take a role in education and moral deliberation on genetic issues. The most public way for the church as an institution to be involved is as a participant in

Public Theology

For purposes of this guide, may be defined as the intentional effort of the church as an institution to engage, influence, support, or criticize the social order from its specifically religious convictions.

social and legal debates. This chapter deals with each of these means and gives special attention to how the church practices what is often called *public theology* (see sidebar). This attention is warranted because the church's involvement in such debate must be carefully thought through if it is to be effective and faithful. Nevertheless, the underlying concern of this chapter is how Christians understand their involvement in the social order and in public debates about genetics.

We will concentrate first on characteristics of our society that effect the nature of public discussion about genetics. The prime concerns include the *pluralism* and *secularity* of contemporary society and the increasing dependence of science and technology upon the dictates of the market. We then explore how Lutherans understand the relation of Christian faith to society, especially through the teaching of the *two kingdoms*. Several key questions guide these explorations. Are there distinctive contributions that faith-based voices (individual, activist groups, and religious institutions) can make to a social debate about genetic topics? In what ways can Christians as citizens speak with explicit Christian convictions in the public arena? On what grounds should a church institution participate in public conversations? How is it actually to be done?



Personal Experience and Values

The conversation regarding genetic developments involves, at some point, the regulation of genetic developments via legislation. Such regulations affect both business and individual choice. Consider then: How much and what kind of regulation should government exercise over the ways biotech businesses operate? What are the criteria to justify government regulation? Should the market be largely unregulated in order to encourage the development of whatever genetic related goods and services citizens may want?

The second issue concerns the nature and legitimacy of religious institutions adopting official stances on public policy and, in addition, advocating for specific pieces of legislation. Should the church officially support or advocate for specific kinds of legislation? What are the criteria to justify doing so? What kinds of legislation? Should the church take a public position only via formal statements, or should they also devote resources to legislative advocacy?

Gathering Input

The Character of Society Today

Church and Society

Many people point to the *disestablishment* of religious organizations in the First Amendment of the Bill of Rights as a prohibition to the church's involvement in the "public square." This clause is often summarized by the term *separation of church and state* and often interpreted to mean that all religious thinking should be excluded from public debates. Yet, the legislation authorizing the Human Genome Project (HGP) explicitly provides 3 percent of its budget for the formation of a task group to consider the Ethical, Legal, and Social Implications (ELSI) of genetic developments. ELSI, in turn, has intentionally invited religious thinkers to contribute explicitly religious reflection. Other invitations for such input at public hearings on cloning, for instance, have also occurred. Some believe that these signs indicate a renewed public desire for religious wisdom to be brought to bear on the difficult questions posed by genetic knowledge and power. If so, this clearly encourages religious voices to enter the public debate.

Contemporary Culture

Other characteristics of the contemporary situation, on the other hand, create special challenges for Christians who seek to contribute to a public debate. *Pluralism* is the term given to one of these challenges. For our purposes pluralism indicates that a dizzying number of quite distinct, even contradictory, religious and philosophical traditions now contribute to shaping the general course of society. Christian churches are not the only religious presence in society. Indeed, the once dominant Christian *mainline* denominations have become one voice alongside many others. For example, Muslims in the United States now outnumber the two and a half million members of the Episcopalian church. Any successful involvement by Christians in public debate on genetic developments will have to take this plurality into account. Contemporary society is often described also as *secular* or *humanistic*. The exact meaning of these terms are debated, but they at least mean that our society has a *this-world* orientation. Religious values and concerns do not carry the authority they once did.

Given these characteristics in U.S. society, how can faith-based voices hope to influence such a diverse and often nonreligious set of beliefs and assumptions? Since Christian talk is explicitly theological, on what basis can the church speak to those who share a different starting point? To oversimplify for the sake of clarifying a point: If a Christian wanted to argue that the Bible forbids tinkering with nature by inserting genes from one species into another, why should a nonreligious scientist find this persuasive? Each religious tradition can certainly influence its own members, but many in our society reject any religiously oriented reasoning as an imposition upon their actions or beliefs. While the relation of Christians to the public order has always been challenging, it is even more complex today.

Science and Society

The changing relationship of science and technology to society during the last two decades also dramatically complicates public debate about the uses of genetic knowledge. Notable science projects of the past (the space program, for instance) were run via centralized bureaucratic structures and depended solely on public funding. Any debate could be directed toward the legislative decisions and government funding that authorized these projects. The Human Genome Project and other government-funded genetic research are dispersed, even decentralized, efforts that involve a mix of public and private finance. Contemporary

scientific research, on the whole, increasingly depends on Wall Street financing and owes increasing allegiance to the specialized public of venture capitalists and shareholders. (These complexities are evident in this guide's discussion of patents or genetically modified organisms.) Such allegiance alters the nature and, arguably, the effectiveness of regulatory oversight.

In considering public policy, three additional observations about genetic developments seem important to note. First, the uncertainty regarding which and how competing moral points of view ought to shape public policy is an uncertainty shared by many of good will, both inside and outside the world of faith. Second, it is a fact of life that public policy seeks the least offensive position to the most people. This is a result of seeking a majority opinion in a pluralistic world. Finally, the speed at which developments occur means that the public policy of today will likely need frequent review.

All of these social realities must be factored into any effort to bring religious voices to bear in the public square. Clearly, this is a complex and challenging task. Nevertheless, many believe that an extended public conversation about genetic developments is urgently needed in order to develop policy that upholds society's best interests and forcefully pursues justice. Many voices, faith-based and otherwise, urge Christians and the church to take such a role in this debate for the sake of the common good.

Theological Considerations

"Faithful participation in society is integral and vital to the mission of the Evangelical Lutheran Church in America. We as individual members and as a corporate body live out our Christian faith in encounter with the concerns that shape life in God's creation." So reads the opening lines of the ELCA document that guides its policies and procedures for addressing social concerns. The genetics' revolution is clearly one of those concerns. How Christians live out their faith in society is the subject of this section.

Twofold Rule of God

The teaching that undergirds the Lutheran understanding of the Christian relationship to society is traditionally called the two kingdoms, or better expressed for today, the twofold rule of God. The biblical idea that Christian live in two ages—the old one represented by Adam and the new one begun by Christ (Romans 5), undergirds the two kingdom doctrine that is found in the Lutheran Confessions of the sixteenth century. The fundamental point is that Christians, as sinful and redeemed people, simultaneously live under God's rule of law and gospel.

The doctrine of the twofold rule provides a way for Lutherans to affirm human society as a place of God's activity and to accept responsibility for it. God works through government, commerce, and other social institutions to establish order and justice. God works, also, though the gospel to create faith. God is equally at work in both realms, even though two different ways are necessitated by the presence of sin. The force of law is necessary to establish peace and order in the social realm. The persuasion of love rules in Christ's realm, a realm begun in the church.

Lutheran ethicists today continue to debate the truth and value of the two kingdoms teaching.³ This teaching has often been interpreted, mistakenly, to encourage a compartmentalized thinking that identifies God's work with religious concerns and excludes God from the public realm. This clearly happened in Nazi Germany where the two kingdoms doctrine was interpreted so as to create an impenetrable border between the political activity of the state and spiritual activity. Sometimes even today the idea of the two realms is wrongly identified with the idea that the church should not attempt to speak on public matters.

Other theologians suggest that the teaching should be understood as a kind of interpretive device. They suggest that the twofold rule of God helps designate the important differences between the areas of life where law dominates and the realm where the gospel is to rule. In this view the point of the doctrine is that "On the basis of a vision of the good life [derived from Christ], the church must show how society may be better. But it is not for the church to be a legislator for society: that is a task for politicians, for the worldly kingdom not the spiritual one. What is a relevant task for the church is to criticize laws and politics." The witness of the church in society is to flow from its identity as a community graced by the gospel and empowered thereby to serve in love and to seek justice. In both realms, then, Christians as Christians are called to be active, but in different ways. This understanding of the twofold rule creates a foundation for entering into public debates about genetic developments, especially when genetic developments threaten the poorest in our society or bulldoze principles of equality and the common good. On



the other hand, the teaching reminds Christians that they too are still part of a fallen humanity. The Christian and the institutional church should be modest when moving into the realm of politics, even though that move is inherently part of Christian mission.

Three Convictions

The following three convictions, elaborated in the ELCA's Social Statement on Church in Society, expand on the idea of what the *twofold rule of God* means for contemporary Christians.⁵

Baptismal Vocation

As mentioned above, Christ's Body is active daily in society through its members as they serve their neighbors. This includes being wise and active citizens who participate in voluntary associations and movements, including prophetic groups that challenge particular immoral or unjust practices. Thus, Christian efforts to serve the neighbor could lead to being a biotech scientist or to being a member of a citizen watchdog organization. Either or both(!) should be a matter of prayerful discernment.

Community of Moral Deliberation

Christians will disagree, sometimes passionately, on the kind of responses that should be made to genetic questions. Yet, Christian unity is founded on Christ and the common convictions of faith, not on moral agreement. Christians are free to celebrate diversity and are called to deliberate together on the challenges faced in the world. This will undoubtedly be the case with genetic issues. In those deliberations, though, scriptural convictions about God's concern for the powerless will emphasize special attention to those harmed by practices related to genetics. In these ways, the Church and its members will seek to "discern what is the will of God—what is good and acceptable and perfect." (Romans 12.2)

Institutional Responsibility

The ELCA as an institution is to serve God and neighbor also in the life and work of its institutions. It is to do so, recognizing that God works through everyday social structures like family and government. In relation to governmental structures, the church is to respect government's God-given integrity and the tasks given to governing authorities. Yet, the church is expected likewise to hold government accountable to God and must ever be on its guard because sin is present and pervasive. The relationship between church and state is often expressed in the phrase *institutional separation and functional interaction*. This view affirms the constitutional separation of church and state without abandoning institutional responsibility. The

Several important characteristics of an effective public theology for genetics' issues include:⁶

Sustained Attention

Public theology initiatives should proceed from a clear theological base and have a sense of priority within the church in order to be taken seriously by the wider society. Sustained attention implies a systematic education and wide-ranging conversation that is needed for credibility.

Timeliness

Public theology must ride with the crest of public attention if it is to be effective. This is difficult, though possible, to coordinate with sustained attention.

Informed and Comprehensible

The church must demonstrate a grasp of the science and issues at stake. It is especially important that the logical relation between theological beliefs and public conclusions must be evident to non-believer. The church's position must demonstrate its relevance for the common good.

Clarity and Focus

Any effective public theology must have a clear and specific focus. It must state what it recommends and why in specific ways that are clear about its justification and reasoning.

church's institutional responsibility includes the pioneering of new ways to address emerging social problems, while it supports institutions and policies that serve the common good.

These affirmations mean that a faith-based involvement in public conversations about genetic questions will include multiple activities. The means will include offering educational resources, fostering moral deliberation in congregations, providing theological reflection, encouraging citizenship, and giving formal attention to public policy. This latter means is the most direct one on the list and leads to a discussion of the ELCA's social policy and its public advocacy ministry.



Institutional Voice

The most authoritative social policy of the ELCA is expressed in documents called social statements. They are theological documents in which the church addresses the question: What ought Christians and the church say and do about a social issue? Such statements are developed through extensive and inclusive deliberation within the church. They become policy only by a majority vote of the churchwide assembly, the church's highest authority. Several current social statements bear indirectly on genetic issues; these include the social statements on abortion, economic life, creation, race and ethnicity. The social statement being developed on health care (to be considered at the 2003 assembly) also will touch upon a number of issues related to medical genetics. A social statement dedicated to genetic developments would be an additional means to present a public witness.

Social policy resolutions represent a second means of public address, but these rely upon already established teachings and social statement policies of the ELCA. The most common form is a message, usually adopted by the ELCA Church Council. Recent messages have addressed immigration, suicide prevention, community violence, and sexuality. Social messages are intended primarily to encourage further discussion and action on specific current social issues. Thus, they provide a timely and more focused means to address social or political

developments. At this writing, there have been no social policy resolutions related to genetic issues.

The ELCA's Ministry of Advocacy

The Constitution of the ELCA, in proscribing the ways in which the church will carry out its mission, directs that it shall "... develop programs of ministry and advocacy to further human dignity, freedom, justice, and peace in the world." [4.03.1]

To carry out these mission directions there is established within the Division for Church in Society a Department for Advocacy, consisting of the following: the Lutheran Office for Governmental Affairs which interacts with Congress, the federal Administration, and the governments of other nations; the Lutheran Office for World Community which interacts with the United Nations; the office for Corporate Social Responsibility which relates the church's positions to the corporate sector; and a number of State Public Policy Offices which advocate with the various state legislative and executive branches of government. These entities work in two directions: 1) Equipping the grass roots of the church for an advocacy ministry; and 2) Speaking the policies and positions of the ELCA directly to public and private decision makers. The most direct activity in which social statements are voiced in the political arena occur through the of the ELCA's advocacy ministry. The ELCA's advocacy staff are not typical lobbyists, but rather are advocates who carry out a range of activities in addition to speaking with legislators. These activities include monitoring political developments, providing education, enabling dialog between contending parties, and others. Advocacy is concerned especially with speaking out, often in tandem with other faith-based voices, on behalf of the voiceless. It is important to note that since all advocacy grows out of ELCA teachings and social statements, little advocacy on genetic concerns has occurred as of this writing.

The question of how faith-based voices could join a public debate on genetics has required a broader look at an understanding of the Christian's and the church's role in society. At this writing, no official policy on any genetic questions has been adopted by the ELCA and no advocacy entailed. Yet, being the church in an age of biological control will require well-informed church members who have given careful thought to the kind of issues represented in this study guide. It may also require the church to raise its voice about genetic developments. Careful thought given now to these concerns by individuals, congregations, and the institutional church will provide invalu-

able preparation when that time comes. Only in this way will the church's voice be credible. Only in this way will the church's faithful participation be possible in the age of biological control.

Deliberation

As an exercise in theological and moral imagination, sketch a social policy message of your own on a genetic issue. You might select one of the topics explored in other chapters of this study guide. Obvious topics include genetic testing, genetically engineered foods, or genetic patents. Be imaginative. Don't worry about perfect wording. The point is to further one's understanding by exercising moral thinking about this topic.



Taking the Conversation with You

The brief exercise above could be developed into a more carefully worded statement as a means of furthering conversation. Even in simple form, it could then be used in several ways. Use it to start a conversation by asking others, in your congregation or at work, to review it and provide feedback. Send a copy to the Department for Studies of the Division for Church in Society of the ELCA as a means of letting the institution know the results of your study. Use it to talk to an ELCA advocate if there is one in your state. A last possibility is to develop the ideas into materials for submission as a resolution to a synod assembly.

For Further Investigation

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

Division for Church in Society. Living the Faith: A Lutheran Perspective on Ethics. (Evangelical Lutheran Church in America, Chicago, 1999).

Evangelical Lutheran Church in America, The Church in Society: A Lutheran Perspective. (1991)

Stumme, John and Robert Tuttle. On Being Christians and Citizens: New Lutheran Perspectives on Church and State (tentative title). (Fortress Press, Minneapolis, 2001).

Citations

1. Audrey Chapman, *Unprecedented Choices: Religious Ethics at the Frontiers of Genetic Science*. (Minneapolis: Fortress, 1999), 109.

The following suggestions will facilitate this exercise. They are drawn from the structure of ELCA social policy messages.

- 1) Choose an issue in genetics that you believe Christians ought to address at a public policy level.
- 2) Create a list of key points to address in the resolution, including a statement of the problem.
- **3)** List the key theological affirmations that will provide the foundation for the message to society. Write an explanatory sentence or two for each of these affirmations.
- 4) Based on this work, write recommendations for this topic. Specify how these recommendations should be pursued. For instance, should these recommendations become a matter of law or should they simply be argued as morally persuasive?
- **5)** Specify the commitments ELCA members and it congregations should make on this topic. Explain briefly.
- **6)** Justify why these recommendations are for the sake of the common good. Remember to argue in ways that can be understood by a pluralistic audience.

Welcome to the task of public theology and genetics!

- **2.** Evangelical Lutheran Church in America, *Policies and Procedures of the Evangelical Lutheran Church in America for Addressing Social Concerns* (1997), 1.
- **3.** Karen Bloomquist and John Stumme, *The Promise of Lutheran Ethics*. (Minneapolis: Fortress Press, 1998); John Stumme and Robert Tuttle, *On Being Christians and Citizens: New Lutheran Perspectives on Church and State* (tentative title) (Minneapolis: Fortress Press, 2001). This is evident, for instance, in the discussion of two kingdoms thinking by the different writers in *The Promise of Lutheran Ethics*. More extensive attention is given to these issues in *On Being Christians and Citizens* (tentative title as of this writing) edited by John Stumme and Robert Tuttle on behalf of the Division for Church in Society of the ELCA.
- **4.** Paul Nelson, "Bioethics and the Lutheran Communion," *Bioethics Yearbook*, Vol. 5; Theological Developments in Bioethics: 1992-1994 (1997), 149.
- 5. Evangelical Lutheran Church in America, The Church in Society: A Lutheran Perspective. (1991)
- **6.** These observations are adapted from the work of Dr. Audrey Chapman, Director of the Program on Science, Ethics, and Religion at the American Association for the Advancement of Science in Washington, D.C. She has written on public theology in several contexts and is an ordained United Church of Christ minister who has served as a staff member of that denomination with responsibilities for several public theology initiatives. See *Unprecedented Choices: Religious Ethics at the Frontiers of Genetic Science* for greater detail.

Glossary

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.

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 acid: any of a class of 20 molecules that combine to form proteins in living things.

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 is withdrawn for testing.

Anencephaly: severe type of neural tube defect in which the top of the brain fails to develop.

APHIS (Animal and Plant Health Inspection Service): An agency of the U.S. Department of Agriculture responsible for regulating the field testing of genetically engineered plants and certain microorganisms.

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.

Autosomal disease: (See Recessive Allele)

Autosomal recessive disorder: disorder where both alleles of an autosomal gene are erroneous.

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 countries' 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.

BRCA1 breast cancer susceptibility gene: a mutated version of BRCA1, which predisposes a person toward developing breast cancer.

BRCA1: a gene that normally helps to restrain cell growth.



B.t. Corn (Maize): Corn that is genetically engineered to provide protection against the European Corn Borer.

B.t. Cotton: Cotton that is genetically engineered to control tobacco budworms, bollworms, and pink bollworms.

B.t. Crops: Crops that are genetically engineered to carry the gene from the soil bacterium Bacillus thuringiensis. The bacterium produces a protein that is toxic when ingested by individual species of insects, thereby providing protection throughout the entire plant.

Carrier testing: testing 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.

Carrier: a person who has a recessive mutated gene, together with its normal allele. Carriers do not usually develop disease but can pass the mutated gene to their children.

Cell: a small, watery, membrane-bound compartment filled with chemicals; the basic subunit of any living thing.

CGIAR (Consultative Group on International Agricultural Research): An informal association of 58 public and private sector members supporting 16 international agricultural research centers. The centers develop advanced breeding material for adoption and use by national agricultural research systems in developing countries.

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: structures found in the nucleus of a cell, which contain the genes. Chromosomes come in pairs and a normal human cell contains 46 chromosomes, 22 pairs of autosomes and two sex chromosomes.

Clone: a group of genetically identical genes, cells, or organisms derived, asexually, from a single ancestor.

Cloning: the process of making genetically identical copies.

Crossing over: a phenomenon, also known as recombination, that sometimes occurs during the formation of sperm and egg cells (meiosis); a pair of chromosomes (one from the mother and the other from the father) break and trade segments with one another.

Cystic fibrosis: an inherited disease 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.

Down's Syndrom: (also known as Trisomy 21) a congenital condition characterized by moderate to severe mental retardation, slanting eyes, a broad short skull and broad hands with short fingers.

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.

DNA sequencing: determining the exact order of the base pairs in a segment of DNA.

DNA: the substance of heredity; a large molecule that carries the genetic information that cells need to replicate and to produce proteins.

Dominant allele: a gene that is expressed, regardless of whether its counterpart allele on the other chromosome is dominant or recessive. Autosomal dominant disorders are produced by a single mutated dominant allele, even though its corresponding allele is normal. (See Recessive allele.)

Edward's Syndrom: (also known as Trisomy 18) a congenital condition characterized by low birth

weight, severe mental retardation, low-set and malformed ears, small jaw, hand abnormalities, congenital heart disease, hernias, and others. Infants who suffer from this condition rarely survive beyond a few months of life.

Enzyme: a protein that facilitates a specific chemical reaction.

EPA (Environmental Protection Agency): A U.S. government agency that issues permits for large-scale testing of herbicides and biotechnology-derived plants containing new pesticidal substances.

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.

Expression: (see gene expression)

Expressivity: the degree to which a gene produces an observable effect or characteristic.

FDA (Food and Drug Administration): A U.S. government agency responsible for ensuring that foods derived from new plant varieties are safe to eat. FDA also has legal authority for food labeling.

Gamete: reproductive cell such as sperm or egg containing a half-copy of the genome.

Gene deletion: the total loss or absence of a gene.

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.

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.

Gene: a unit of inheritance; a working subunit of DNA. Each of the body's approximately 50,000 genes contains the code for a specific product, typically, a protein such as an enzyme.

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.

DNA techniques: Definitions used in Europe tend to be broader.

Genetic linkage maps: DNA maps that assign relative chromosomal locations to genetic landmarks—either genes for known traits or distinctive sequences of DNA—on the basis of how frequently they are inherited together. (See Physical maps.)

Genetically Modified Organism (GMO): 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 GMOs.

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 maps: charts that indicate the ordered arrangement of the genes or other DNA markers within the chromosomes.

Genome: The sum of the genetic material in the chromosomes of a particular organism; a complete set of haploid chromosomes.

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.

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's disease: 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-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 beginning at a few months of age.

Immunology: the study of the immune system which fights infection.

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.

Lesch-Nyhan syndrome: a genetic disorder due to lack of an enzyme, characterized by self-mutilation by biting.

Linkage analysis: a gene-hunting technique that traces patterns of heredity in large, high-risk families, in an attempt to locate a disease-causing gene mutation by identifying traits that are co-inherited with it.

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 change in the number, arrangement, or molecular sequence of a gene.

Neoplasm: abnormal new growths, either malignant cancers or benign tumors.

Newborn screening: examining blood samples from a newborn infant to detect disease-related abnormalities or deficiencies in gene products.

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.

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.

Pharmacogenomics: (See Pharmacogenetics.)

Phenotype: the observable characteristics of gene expression. (Compare with genotype.)

Phenylketonuria (PKU): an inborn error of metabolism caused by the lack of an enzyme, resulting in abnormally high levels of the amino acid phenylalanine; untreated, PKU can lead to severe, progressive mental retardation.

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.

PKU: see Phenylketonuria

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.

Predictive gene test: tests to identify gene abnormalities that may make a person susceptible to certain diseases or disorders.

Prenatal diagnosis: examining fetal cells taken from the amniotic fluid, the primitive placenta (chorion), or the umbilical cord for biochemical, chromosomal, or gene alterations.

Probe: a specific sequence of single-stranded DNA, typically labeled with a radioactive atom, which is designed to bind to, and thereby single out, a particular segment of DNA.

Prostate Specific Antigen (PSA): cell marker measured by blood test that can be used to screen men for prostate cancer.

Protein: a large, complex molecule composed of amino acids. The sequence of the amino acids—and thus the function of the protein—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.

Recessive allele: a gene that is expressed only when its counterpart allele on the matching chromosome is also recessive (not dominant). Autosomal recessive disorders develop in persons who receive two copies of the mutant gene, one from each parent who is a carrier. (See Dominant allele.)

Recombinant DNA (rDNA): DNA produced using genetic engineering techniques. Such techniques involve transferring a DNA segment from one organism and inserting it into the DNA of another, possibly unrelated, organism.

Recombination: (See Crossing over.)

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.

Screening: a medical test used for certain populations to screen for telltale products of genetic material known to cause disorder. The findings of a screen often include false positives and only an additional test can be determinative.

Sequencing: (See DNA sequencing.)

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, the oxygen-carrying pigment in the blood, causes distortion (sickling) and loss of red blood cells, producing damage to organs throughout the body. As a recessive gene, it can be expressed as either sickle cell trait when derived from only one parent or as a full-blown anemia when inherited from both.

Somatic cells: all body cells except the reproductive 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.

Toxic Knowledge: genetic information about a statistically probable onset of, or disposition to, a disease or disorder for which there is no cure.

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.

Transgenic Plants: Plants that result from the insertion of genetic material from another organism, generally through recombinant DNA techniques, to make the plant exhibit a desired trait.

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: the swapping of a genetic material from one chromosome to another.

Trisomy: three copies of a chromosome per cell, which causes disease. one example. One example is Trisomy 21 (three copies chromosome 21), commonly known as Down Syndrome. Trisomy 18, or Edwards Syndrome, is another example.

Trisomy 18: see Edwards Syndrome

Trisomy 21: see Down Syndrome

Variable number of tandem repeats (VNTR): some sequences of DNA are repeated many times in a row. The number of repeats may not be identical in offspring. This can lead to disease and can be used in forensics to identify individuals.

X chromosome: a sex chromosome; normal females carry two X chromosomes.

Y chromosome: a sex chromosome; normal males carry one Y and one X chromosome.

Sources: *Understanding Gene Testing* National Institutes of Health, National Cancer Institute; *Genetic Testing and Screening* Division for Church in Society, ELCA; U.S. Department of Agriculture; Organization for Economic Cooperation and Development; U.S. Congress, Office of Technology Assessment.

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www.ornl.gov/hgmis/project/info.html;

 $www.ornl.gov/TechResources/Human_Genome/home.html$

http://biology.about.com/science/biology/msub6.htm

www.elca.org/dcs/genetics.study.html



Ordering Information

For ELCA publications noted in the text

ELCA Resources

Genetic Testing & Screening: Critical Engagement at the Intersection of Faith and Science A multi-authored volume on the issues surrounding genetics from a Christian perspective. AFP 34-11-2108 (ISBN 1-886513-11-2), \$10.00 (1998)

Human Cloning: Papers from a Church Consultation
This multi-authored volume addresses the challenges posed by cloning from a faith-based perspective.
AFP 69-1550 (ISBN 6-0001-3165-8), \$5.00 (2001)

*The Promise of Lutheran Ethics*A multi-authored volume on the Lutheran approach to ethics.
AFP 1-3132 (ISBN 0-8006-3132-3), \$18.00 (1998)

Talking Together as Christians about Tough Social Issues
A six-session introduction on how to begin conversation on tough social issues.
AFP 69-8681 (ISBN 6-0001-1197-5), \$1.00 (1999)

ELCA Social Statements

A Social Statement on Abortion
The ELCA's social statement on abortion.
AFP 69-0062, 15¢ (1991)

A Social Statement on Caring for Creation: Vision, Hope, and Justice The ELCA's social statement on the environment. AFP 69-1380, 10¢ (1993)

The Church in Society: A Lutheran Perspective The ELCA's social statement on church in society. AFP 69-2102, 10¢ (1991)

A Social Statement on Economic Life: Sufficient, Sustainable Livelihood for All The ELCA's social statement on economic life. AFP 69-8615, 35¢ (1999)

ELCA Procedural Documents

Policies and Procedures of the Evangelical Lutheran Church in America for Addressing Social Concerns Details the manner in which the ELCA chooses a social topic to study and the processes it goes through to make it ELCA policy.

AFP 69-7440, 25¢ (1998)

How to Order

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