

Toward a Lutheran Ethic in the Age of Genetics

Gathering

HYMN

(See hymn suggestions on p. 119)

PRAYER

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

(*Evangelical Lutheran Worship*, page 86)



HEARING THE WORD

Romans 12:1-8

DISCERNING THE WORD

Silence

Discernment

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

Introduction

Session summary

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



Real life stories

(choose one for careful reading and discussion use)

1: Prenatal genetic testing

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

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

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



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

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

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

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

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

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

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

2: Labeling for genetically modified food sources?¹

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

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

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

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

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

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

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

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

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

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

Toward a Lutheran ethic in the age of genetics

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

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

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

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

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

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

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

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

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

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

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

Shall we embrace a precautionary principle?

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

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

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

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

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

Shall we consider long-term social and economic impact?

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Conclusion—redeemed decision makers

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

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

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

Invitation to conversation, prayer, and action

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

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

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



Questions to use:

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

Closing prayer

Invitation to intercessory prayer

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

Praying with the tradition

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

(*Lutheran Book of Worship*, page 44)

Endnotes

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

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

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

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