

GENETICS-RELATED RELIGIOUS ISSUES:
Findings from a Clergy Leaders' Conference

*A White Paper prepared April 2002 for the
Ethical, Legal and Social Implications (ELSI) Program
of the Human Genome Project (HGP)
United States Department of Energy (DOE)*

by Paul Sullins

*Life Cycle Institute, The Catholic University of America
Washington, D.C. 20064*

Introduction	2
Genetics-related Religious Issues.....	3
Macro-Level Issues.....	4
Micro-Level Issues	7
Conclusion	10
Appendices	
1. Selected Bibliography	12
2. “God, Grace and Genetics” A sermon by the Rev. Susan Andrews	14
3. “Genetic Engineering” A meditation by the Rev. John Wimberly, Jr	18
4. References	22

Donald Paul Sullins, Ph.D., is an assistant professor in the Department of Sociology and an Associate Member of the Life Cycle Institute. Dr. Sullins has conducted studies on the clergy and religious groups since 1994, authoring papers that have appeared in *Social Forces*, *Sociology of Religion*, *The Catholic Social Science Review*, and the *Journal for the Scientific Study of Religion*.

Introduction

The rapid advance of knowledge and technology regarding the human genome has raised a number of important issues--new and old--for religious traditions. To the extent that DNA is seen to be central to species and individual identity, the powers that we are now obtaining over it naturally stimulate reflection or concern regarding the nature and meaning of human life itself. While religious traditions have generally endorsed the manifest potential of biotechnology to improve human health and well-being, they have also cautioned against its unintended consequences. These concerns are evident not only in the lofty levels of theology and moral philosophy but also in very practical, pastoral dilemmas presented by the increasing importance of genetic information in workplace, family and health care decisions. For the most part, however, genetic knowledge has not informed religious ethical reflection. With a few notable exceptions, ethicists operating within religious traditions and scientists pursuing genetic advances have operated independently of one another. In part this is due to the increasing specialization and technical complexity of genetic knowledge; in part also to the cultural segmentation of "scientific" and "religious" discourse; and in pertinent part, to the lack of mediating social structures that provide an arena in which scientific and religious dialogue can occur.

As a step toward addressing this problem, for three days in April 2001 at Berkeley Springs, West Virginia, a Pilot Conference on genetics, religion and pastoral issues was sponsored by the ELSI (Ethical, Legal and Social Implications) Program of the U.S. Department of Energy (DOE) affiliated with the Human Genome Project (HGP). Conducted by Catholic University's Life Cycle Institute for Religious and Social Research (LCI), the conference brought

together religious leaders to consider how faith groups in America could better address and cope with ELSI-related issues as the Human Genome Project nears completion of its work in the next few years.

The conference had two stated purposes: 1) to assess a preliminary model of education for pastoral leaders to bridge the gap between scientific and religious discourse; and 2) to identify the religious and/or pastoral issues arising from emerging genetic possibilities, from the standpoint of clergy leaders as distinct from theologians or academics. This white paper reports the conference findings regarding the second of these purposes. A separate process report presents the work of the conference regarding the first purpose.

Genetics-Related Religious Issues

The issues at the intersection of religion and biotechnology range from the profound to the practical. On the one hand are Faustian questions (such as, e.g., those raised by Roger Shattuck) of whether knowledge of the human genome is intrinsically devaluing to human dignity, a Pandora's box leading to post hoc regrets. On the other hand are more specific concerns about genetic discrimination, privacy and consent for testing. We might define a middle range dealing with beginning- and end-of-life issues or even eugenics. In addition, religious ideals may inform social policy proposals regarding patents, intellectual property, or the role of the market.

As stated above, a major goal of the conference was to map the relations among these ideas and determine the salience of each set of issues for clergy. To this end, prior to the conference, participants reviewed selected writings that surveyed the current state of the discussion of similar issues among theologians and ethicists. They also contributed white papers, articles, official statements, legislative texts and colloquia from their respective

denominational bodies, which were circulated to all participants for review and comment. At the conference, following the "boot camp" genetics education experience, a structured discussion guided the participants in the identification of those issues that were most salient or important. Two classes of religious issues emerged from this analysis, correspondingly roughly to the macro and micro levels of analysis: collective issues of broad concern for theological reflection or public policy; and issues attendant to pastoral practice and intervention.

A. Macro-Level Issues

Three sets of macro-level issues related to genomics technology were identified as most salient for collective religious reflection and activity. These are 1) issues regarding human identity; 2) concerns about the commodification of genome properties and genetic therapies; and 3) the problem of establishing boundary principles that at the same time discourage destructive activities and encourage positive outcomes in the exploration of new genetic possibilities. The conference formed working groups to develop themes, attendant questions and related religious affirmations for each of these issues. What follows is a reviewed summary of the working group reports.

1. Human Identity

What are the proportional contributions of a) genes, b) environment, c) personal will and d) God's grace to shaping who we are? Are these distinctions real or only analytic? These questions were considered pivotal to a proper religious response to genetics issues.

Attendant questions were:

- How do we reconcile the genetic ideal of "normality" with the Christian ideal of perfection? Perhaps "authentic" is a better category than "normal" to describe human flourishing.

- Are mutant genes expressions of deformity or diversity? Are mutant genes related to sin? What is the role of grace in “random, exogenous” mutations, and the specification of any individual human genome?
- How does the desire for genetic enhancement relate to the doctrines of salvation and sanctification? Is salvation best understood in this context as perfection or purity, or as becoming whole, balanced or integrated?
- Since suffering can be redemptive, we must ask, when we move from treatments to enhancements, whether we may by genetic “fixes” end up avoiding suffering that may otherwise be beneficial. When the adjustment of persons and families to enhancements is taken into account, many enhancements may in fact cause more suffering than they relieve.

Affirmations that were agreed on were:

- We affirm that in the ordering of our collective and individual genomes grace is present from the beginning, orienting us toward the transcendent. Human persons are both created and creative. Within limits, we (unique among creatures) choose and create our own environments as part of full human development, working with God both to fulfill and to transcend our genetic heritage.
- We affirm that freedom is always limited, yet we are always free within limits. Human persons are both limited and free.
- We affirm that all humans, without exception, are created in God’s image.
- We affirm (with “process theology”) that God is a continuing presence in creation, who is internal and intrinsic to the created order. Eternal life, therefore, is the one we have already begun (a “realized eschatology”); and creation is not finished yet.
- We affirm (with the Westminster Catechism) the goal of humanity that that the “chief end of man is to glorify God and enjoy him forever.”

2. Commodification

The issue of the just and fair distribution of beneficial genetic therapies is clearly a matter for moral and religious, not just economic or scientific, concern. Based on past experience with the diffusion of new technologies, the conference participants were skeptical that market forces alone would encourage fair and affordable distribution of genomic therapies. On the other hand, drawing on the example of the environmental movement, they were very hopeful about the

ability of government to encourage just distribution through pragmatic engagement with the marketplace. Thus the question at the focus of this concern is the pragmatic one of how to encourage or structure the market to develop and distribute genomic therapies in a just way.

Since, as the Universal Declaration on the Human Genome affirms, the human genome is the common heritage of humankind, the benefits of understanding the genome should be readily available to all. Thus genes (i.e. alleles) should not be patentable at all and should be guarded as our human genetic heritage, but recombinant DNA vectors and procedures could be patentable. Moreover, revenue created by these patents should carry some kind of "social contract" dimension such that a proportion would be set aside to provide genetic therapies for individuals who might not have financial resources for such treatment and/or to fund genetic therapies for individuals suffering from "orphan diseases" which may not be considered profitable by the biotech industry.

3. Boundary Principles

“How do we set limits or derive ethical standards that establish a balanced middle ground between reactionary alarmism and uncritical acceptance of new genetics technologies?” With this question, the conference participants called for a basis for ethical standards that would address both the risks and the potential benefits of genomics research.

The participants produced the following set of assertions as an initial statement of this problem: “Personhood is more than the sum of its economic, social and scientifically-observable parts. Created in the image of God, human life is unique and sacred. Knowledge itself is good, but can be used either to affirm or to devalue personhood. Genomics increase our knowledge and are capable of great advances in human health and life. The misuse of genomics knowledge is also capable of great harm to humanity. Therefore ethical guidelines need to be established

which will encourage responsible development of genomics knowledge and prevent abuse and exploitation.”

B. Micro-level Issues

Pastoral care is the art and discipline of care for human persons in that includes the dimension of faith. The official statement of the Association of Professional Chaplains (formerly the College of Chaplains) and the National Association of Catholic Chaplains establishing Pastoral Care Week says: "The pastoral caregiver crosses institutional, economic, cultural and ecclesiastical boundaries to present a God who demonstrates a desire for healing and wholeness in human life. . . . Among other values, pastoral care demonstrates a dedication: to human dignity, to appreciation of individual differences, to a balance of acceptance and accountability, to a dedication to justice and mercy, and to an incarnation of love and hope."¹ Care for persons becomes pastoral when the caregiver "focuses the relationship upon the relation of God to the process of their lives".² This *pastoral* dimension provides added value to the otherwise secularized helping professions, i.e., psychiatry, ethics or social work, such that "instead of being a dialogue, a *trialogue* comes into being".³ In the caring relationship, the pastoral caregiver functions as a prophet, that is, one who points to God and brings to bear a tradition of faith, and an ethicist. Most importantly, however, the pastoral caregiver confers what pastoral theologians call the "pastoral blessing", which involves confession, guidance for decision-making, and the possibility of forgiveness.⁴

How will genetics advances affect the practice of pastoral care? The prediction of such pastoral cases likely to arise as a result of genetics advances is an important task to help churches and pastors prepare to address them. However, this question must first be asked in the past tense, for in fact pastors are already faced with genetics-related pastoral interventions. Unlike the

hypothetical issues that concern ethical and legal thinking and the projections that form the basis for public policy concerns, pastoral reflection is typically focused more narrowly on practice. While not operating in a vacuum with respect to concerns of ethical casuistry and public policy, pastoral care is specifically concerned with spiritual counsel and the application of religious principles to the needs and struggles of persons in individual circumstances.

As a first step, then, toward understanding genetics-related pastoral practice issues, the conference participants took an inventory of the cases involving genetics technologies that had risen in their pastoral practices in the past two years. Each participant contributed from one to five cases. We recognize that an accurate statistical prediction would involve resources and methodology that are far beyond the limits of a single small conference, and no claim is made regarding the representativeness of this sample.

As summarized below, some cases are completed interventions, and some conclude with questions. All cases are derived from actual experience, not hypothetical projections, however details may have been changed to safeguard confidentiality. The cases fall into three groups, comprising pastoral issues regarding A) genetic testing, B) reproduction and C) family history.

1. Genetic Testing

- A female graduate student, 26, (presenter) discovered her mother had Huntington's Disease (HD). The mother was racked by guilt regarding what she may have passed on to her children. With her own testing for HD at issue, presenter sought the most loving response to her mother consistent with self-care, in the context of God's grace for both. After counseling she declined to be tested.
- Male presenter age 28 discovers he has Muscular Dystrophy (MD). While he struggles adequately to cope, his mother becomes alcoholic over the guilt of passing the disease to her son.
- Presenter's mother was diagnosed with breast cancer, a dominant gene (BRCA-1). Subsequently presenter, a female in her early 30s, learns that two aunts have had early breast cancer. Should presenter be tested?

2. Reproduction

- Mother dies at age 56 of early-onset Alzheimer's Disease. Son, age 35, wonders if he should be tested. He owns a successful corporation valued in excess of ten million dollars. If the test is positive, should he sell the business while he still can manage his affairs?
- Husband has family history of low intelligence, low birth weight (LBW) male babies. This was a problematic issue prior to marriage. The first son had LBW and low intelligence. The second son had LBW but normal intelligence. The couple wants a girl and morally opposes elective abortion. Should they consider a third pregnancy?
- Woman aborted one of two monozygotic male twins. Her son is now 11. She is obsessively protective of the child. What pastoral intervention, if any, should be made?
- After the first child was a girl, a couple tried again hoping to beget a boy. They now have five girls. Although the church opposes reproductive interventions for sex selection, they are considering some options of that type.
- Childless couple, both with severe learning disabilities, consider forgoing intrusive reproductive therapies to adopt. The potential adoptee is a bright child, with no learning disabilities.
- Female age 35 has persistent endometriosis. She cannot afford in vitro fertilization, so has given up on having children. Her husband wants to try a normal pregnancy; the couple have separated over the issue. How best to help?
- Pregnant female age 40 is advised to test for Down's Syndrome (DS). The church opposes abortion except when the mother's life is threatened. She doesn't think she could provide adequate care for a DS child. Should she be tested?

3. Family Histories

- As an incidental result of DNA health screening, a male age 40 discovers he is not his father's genetic child. Pastoral counseling led to family confrontation and an open family conference. After a personal search, the respondent discovers his father is a famous Brazilian polo player, with whom he must make contact for medical reasons.
- The presenter's uncle has severe depression. Two of three third cousins have depression. The pastor discovers an extended family history of depression, but no sharing or communication regarding the problem, such that none of the sufferers saw it as a family or genetic-related problem, or sought treatment accordingly.

- In consulting on a case in which family histories are being taken, extended relatives object to the intrusiveness of the information requested. The question presented to the pastor regards ownership of the family history. How should the pressing need for family information, or to communicate a genetic problem, be balanced with the desire not to invade the privacy of distant relatives back up the germline?
- An Institutional Review Board (IRB) in a medical institute seeks advice from the chaplain regarding the use of cloned tissue stock taken from a patient who is incompetent to give consent.
- A patient waiting for a liver transplant is visited twice a week by his pastor. At the start of each visit he asks, "Have they found a gene [to cure my condition] yet?" How should the pastor respond?

Conclusion

The concerns of religious professionals and caregivers regarding genetics advances are both like and unlike those of other constituencies in the national conversation about the implications and uses of the HGP. Like theologians they are stimulated to reflect about the meaning and limitations of human personhood, and like ethicists they wish to derive principles to guide decisions. These issues, however, are matched by concern about the social uses and distribution of genetics technologies. All of the broad issues posed by clergy professionals are closely linked to pragmatic, multivalent sensitivities to the complexity, not only of the technical possibilities involved, but also the social ends to which those possibilities may be directed. As much as can be inferred from a very limited sample, their experience thus far consists not only of helping persons make decisions regarding genetic testing but also caring for persons facing the difficulties of increased control and specificity in reproductive choices as well as the new criticality imposed on family communication.

Whether or not these cases adequately portray the current or predict the future range of genetics-related pastoral interventions, it is clear that clergy responding to the implications of genomics advances will be oriented more to practice than to theory, to the resultant of many

interests and concerns than the single-minded pursuit of only one, and to what works to help people than to what fulfills a doctrine or an ideology. This flexibility and balance, the wholepersonal perspective of a generalist rather than the narrow view of an "expert", may well be critical to resolving--or more likely, managing in the absence of resolution--the knotty problems posed by the diffusion of genomics knowledge. As one prominent voice, Dr. Alan Guttmacher, has put it, "In our society, individuals historically look to faith-based organizations for discussions of ethical issues. . . . Maybe the most important thing faith-based organizations can do right now is to let people know that this is a group of issues *they* should have some real impact on. We read in newsmagazines about things like cloning and Dolly, for example, but many other issues are much more pertinent to the average person's daily life. It would be wonderful to have faith-based organizations involved in--perhaps even *leading*--those conversations."⁵

SELECTED BIBLIOGRAPHY

The following list represents the most significant materials used in the preparation of the conference, contributed by participants, or referred to in the conference report. The books by Cole-Turner and Leroy and Palmer below present comprehensive bibliographies of the theological and ethical literature on genetics issues. Both publications by Willer provide a full review of the pastoral and ecclesiological (church-related) literature.

Buchanan, Alan, et al. 2000. *From Chance to Choice: Genetics and Justice*. New York: Cambridge University Press.

Burgess, John P., ed. 1998. *In Whose Image? Faith, Science, and the New Genetics*. Louisville, KY: Geneva Press.

Caplan, Arthur L. 1997. *Am I My Brother's Keeper? The Ethical Frontiers of Biomedicine*.
Bloomington, IN: Indiana University Press.

Cole-Turner, Ronald. 1997. *Human Cloning: Religious Responses*. Louisville, KY: Westminster John Knox Press.

Hubbard, Ruth and Elijah Wald. 1998. *Exploding the Gene Myth: How Genetic Information is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators, and Law Enforcers*. Boston: Beacon Press.

Junker-Kenny, Maureen, and Lisa Sowle Cahill. 1998. *The Ethics of Genetic Engineering*,
(Concilium 1998:2) Maryknoll, NY: Orbis Books.

Kilner, John F. et al., eds. 1997. *Genetic Ethics: Do the Ends Justify the Genes?* Grand Rapids, MI: Eerdmans.

Oates, Wayne E. 1974. *Pastoral Counseling*. Philadelphia: Westminster Press.

Parens, Erik, ed. 1998. *Enhancing Human Traits: Ethical and Social Implications*. Washington, DC: Georgetown University Press.

Peters, Ted, ed. 1998. *Genetics: Issues of Social Justice*. Cleveland, OH: Pilgrim Press.

Peters, Ted. 1997. *Playing God? Genetic Determinism and Human Freedom*. New York and London: Routledge.

Rifkin, Jeremy. 1997. *The Biotech Century: Harnessing the Gene and Remaking the World*. New York: Penguin Putnam.

Shattuck, Roger. 1996. *Forbidden Knowledge: From Prometheus to Pornography*. New York: St. Martin's Press.

Shinn, Roger L. 1996. *The New Genetics*. London: Moyer Bell.

Walters, Leroy, and Julie Gage Palmer. 1997. *The Ethics of Human Gene Therapy*. New York and Oxford: Oxford University Press.

Willer, Roger A., ed. 1998. *Genetic Testing and Screening: Critical Engagement at the Intersection of Faith and Science*. Cleveland, OH: Pilgrim Press.

Willer, Roger A., ed. 2001. *Human Cloning: Papers from a Church Consultation*. Chicago, IL: Evangelical Lutheran Church in America.

A sermon preached by
Susan R. Andrews
May 6, 2001

TEXT: Genesis 1:26-31

GOD, GRACE, AND GENETICS

Because of your tax dollars, I had a wonderful experience last week. The multi-billion dollar Human Genome Project, funded by the Department of Energy and the National Institutes of Health has included in its budget a 4% set aside to be spent on exploring the ethical and spiritual implications of this astounding research. So, at the end of April twelve mainline Protestant clergy were pulled together at a lovely conference center in West Virginia. We were asked to talk about the "Pastoral Implications of the Human Genome Project." I was invited thanks to you - or I should say, thanks to Tom Ward.

Ten years ago, when this whole idea of sequencing the genetic structure of human beings still seemed like science fiction to most of, Tom and others in this church saw what was coming - a magnificent step forward in unraveling the mysteries of how we are made - with all kind of possibilities for healing disease and relieving suffering. But also with the scary possibilities of "playing God" - of deciding what is normal, what is beautiful, what is acceptable within the human body. And so, in 1991, our Session, through National Capital Presbytery, overtured the General Assembly of the Presbyterian Church (USA) to study this issue and begin to wrestle with the ethical and social implications of such wonderful and fearful knowledge. The result of all that was the publication last summer of a book of essays written by a variety of Presbyterian scientists and theologians - including our own Parish Associate, Jim Miller. And I got to spend three days in a lovely place, immersed in a crash course on genetics.

A word of warning.. I barely passed Biology and Chemistry and Physics in high school - it was only my meticulous lab work that pulled me through. So if I mutilate scientific theory and vocabulary in any way this morning, I apologize to all you micro- biologists and research physicians sitting in these pews.

If you have been reading the papers in the last month or so, you know that the folks at the NIH working on this, as well as a private research corporation here in Rockville, have both just completed mapping, or naming, the sequence of genes that are the building blocks of the 23 chromosomes each one of us have in our bodies. It is important to know that they have mapped *a* human genome - not *the* human genome. In God's winsome design, there is infinite variety among human beings - and though this new genetic information is valuable, it doesn't completely describe the unique protein structure of each one of us.

The simple definition of a gene is "a factor on chromosomes that control characteristics or traits." Genes are made up of nucleotides - there are more than 3 billion nucleotides in an average human being, and each gene is composed of anywhere from 500 to 100,000 nucleotides. It is the combination of nucleotides that create the particular chemical structure of a gene - which then provides instruction for the production of proteins. Got It? That leads to who we are - the color of our eyes, our bone structure, our height, our intelligence, our skin color - you name it. There are wild genes - which are what normal genes are called - and there are mutant genes - and that's where breast cancer and Alzheimers and dwarfism and congenital blindness and other human trauma gets started. Obviously, now that we know where those genes are and what they are, in theory and soon in practice - we will be able to just remove the bad gene, and replace it with a good gene - and voila! the problem is fixed! But it isn't that easy - either scientifically or ethically.

Two astonishing findings emerged from the recent mapping of a human genome. First of all - since yeast has 6000 genes and fruit flies have about 30,000 genes, scientists were pretty sure that we complex and magnificent human beings must have at least 60,000 or even 100,000 genes. Well they were very wrong. What they discovered was that we have about 38,000 genes - very close to our cousin the fruit fly! So much for the superiority of humanity! The other discovery had to do with variety - instead of just a "wild or normal gene" and a mutant gene, there are many variations of what are called alleles - up to 550 variations when you consider the gene controlling cystic fibrosis alone. Simply put, that means that there are no easy answers - either to what is "normal" - or to what causes particular forms of behavior or disease.

Now the question for us this morning is what God has to do with all of this - and, because we are God's creation - what we have to do with it. Our scripture reading for today makes it clear that we have a dilemma. According to the creation stories in Genesis, God is the creator, the designer, the source and wonder of all creation - and we, as those created in the image of God are to be the stewards, the protectors, the care takers of God's creation. The word "image" in Hebrew is *selen* - which literally means "statue". So we are God's statue, God's representative, God's "stand in" in this world. And the uniquely human way we "stand in" for God is through thinking, through our valuing, through finding meaning and purpose in the world around us. So, from the biblical perspective, this whole genomics effort seems to be part of being Co-Creators with God - our human action as part of the evolutionary unfolding of creation. (Thanks to Cynthia Crysdale for this thought). And it is a fearful thing - fearful in scripture meaning both "awesome" - full of wonder - and "terrifying" - full of danger.

So, let me just sketch a few responses which we as people of faith might make to this awesome, dangerous knowledge that those with God given talents have just unraveled for us.

1. As people of faith, we are to acknowledge the wonder, the creativity - yes even the holiness - of what has just been discovered. Such knowledge does not threaten the providence and sovereignty of God. It just leads to bigger questions and as Wendell Berry suggests it "...just pushes back and enlarges the circumference of mystery." Or as Francis Collins, the head of the NIH Human Genome Project - who is also an evangelical Presbyterian - as Collins says: "What we have discovered is far grander than our genetic instruction. What we are seeing and hearing is the very Language of God."

2. We, as people of faith, must constantly look at the big picture - and encourage the scientific community to do the same. God is big enough to embrace all this terrifying knowledge we have just discovered - and big enough to worry about the consequences - and so should we. One scientist who has created a robot has suggested that there is no danger in what he has done, because this robot only plays soccer. But as another person pointed out to him, the technology he used to create his robotic playmate, is the very same technology undergirding tomahawk missiles. Yes, my friends, we must be very careful with this wonderful knowledge.

3. As people of faith, we must question and demolish the "gene myth" - the assumption that our genetic map completely controls us - that our genetic imprint is somehow the new definition of the soul. We know that in our own lives, environmental factors, personal will, and most of all the grace of God shapes us just as much as our biology. The complexity and wonder of who we completely are is God's gift to us - and this new scientific information does not change that elegant mix. As studies of identical twins suggest, who grow up to be very different from each other, we are much more than our biology.

4. As people of faith, we must ask the theological and ethical questions related to these genetic discoveries. And as people of politics and social conscience we must make sure that these questions are being asked where they matter - at the governmental level and at the marketplace level. Creating large and flexible boundaries with clear values will insure freedom and safety, within those boundaries, to do wonderful things - while hopefully avoiding the terrible things.

What *does* it mean to be human? Does it mean to be tall, thin, muscled with blue eyes, blond hair, and an IQ of 160? We may soon be able to design such wonderful creatures. If we begin to breed out certain mutant genes what will we miss? If we breed out homosexuality what about the creative wonder of gay people like Michelangelo and Walt Whitman. If we breed out deafness might we lose such marvels as Beethoven's Ninth

Symphony, composed when he was totally deaf? What is the definition of “normal” and “healthy?” Is it not the balance of mind, body, spirit and heart - no matter what one’s genetic predisposition?

At a recent conference of the Little People of America, emotions were running high about the implications of gene therapy for the world of dwarfs. It is now clear that the gene for dwarfism is attached to chromosome #4 and can be easily detected through genetic testing. So the assumption is that prospective parents could discover this gene and decide to have an abortion. Except that some parents who are dwarfs are appalled at the thought - worried about becoming an endangered species. As one dwarf mother put it: “We talk about being a society that celebrates diversity. But we implement these tests that get rid of the ones who are different.”

5. As people of faith, how do we balance the creative impulse of God to provide endless variety in nature, with the role of Jesus as healer -as one who relieves suffering? Is it not the compassionate thing to do to give a short boy growth therapy so he can feel normal? Or is it more important to help him embrace his small stature as part of the dignity and diversity and uniqueness of his particular human presence in the world? Are we trying to eliminate difficulty and suffering, when as Christians we have a core story that embraces suffering and finds meaning within it? On the other hand, if we can increase the quality of life for one of God’s children, are we not obligated to do so? One of the men in our group, an Episcopalian priest who also engages in genetic research, told us about a couple in his parish - 83 year old parents of a severely schizophrenic daughter. Every week they ask him “Have they found the gene yet?” Havel they found the gene that will give their daughter relief from her demons and peace of mind for these weary parents who do not have much time left.

6. As people of faith we must continually ask about the consequences of using this new information. If we clone a healthy liver for transplant, isn’t that a benevolent use of this technology? But if we clone a human being - for selfish or utilitarian purposes - does that not violate God’s intention of diversity in creation? And what kind of dignity and spiritual identity does the clone have? The United Nations has issued an international declaration condemning human cloning. But it is coming, whether we want it or not. To clone or not to clone, may well be the 21st century battle equivalent to the abortion wars.

And what about genetic testing? If I find out at age 51 that I have the Alzheimers’ gene - a distinct possibility because of my mother and my grandmother - what do I do with that information - since there is no cure for Alzheimers? Do I live in fear and trembling for the rest of my life?

What about eugenics - the altering of life permanently through germ line therapy? If my daughter should eventually conceive a child and the discovery was made that the fetus is carrying the gene for Huntington’s disease, is it ethical for her to have the bad gene removed and a good gene put in *in utero* - thus altering all the generations to come? Our experience with genetically altered food has shown us that we don’t know the consequences of what we do. Is it fair to experiment at the expense of future generation - particularly without their consent?

Finally, there are issues of the marketplace. If genetic research and technology becomes privatized where will the ethical controls come from? Will only the rich be able to afford the rewards of genomics? And what happens to the poor and the uneducated - not only in this country, but around the world?

Yes, my friends, this is mind boggling, marvelous, dangerous, mysterious stuff. Ethicist Cynthia Crysdale (Catholic University) sums up the challenge for all of us people of faith: “The key foundational task is to turn the study and use of genetic information into matters of wonder and gratitude rather than exploitation and consumption.” (Unpublished review.) Brothers and sisters, it would be an act of ignorance, cowardice- yes even sin - to disdain or avoid what is happening in the world of microbiology. But it would be equally profane to let it unfold without rigorous engagement with the ethics and theology of our faith.

An old Jewish folk tale makes clear the essential role we must play in the unfolding drama of creation. “One day God said to Abraham, “If it weren’t for me, you wouldn’t be here,” to which Abraham replied, “True, but if I weren’t here there wouldn’t be anyone to think about you.” or thank you. (Barbara Brown Taylor, *The Luminous Web*, p. 30) My friends, let us embrace our vocation - “to think about God” and thank God - to glorify and embody and enjoy God forever - even within this whirlwind of new knowledge that tumbling down around us every day.

May it be so - for you and for me. Amen

Appendix Three

Genetic Engineering

a communion meditation by

John W. Wimberly, Jr.

Pastor, Western Presbyterian Church

Washington, D.C.

May 6, 2001

Text: Genesis 6:1-8

God was furious. Adam and Eve couldn't follow the most simple of directions ("Enjoy the garden but don't mess with the trees!" God told them. So what did they do? They messed with the trees.). Relationships between siblings like Cain and Abel routinely devolved into bloody violence. As a result, says the Book of Genesis, God decided to start over again. "These folks are hopeless. I'm going to wipe the slate clean with a flood and start over," said God.

Archaeologists, geologists and other scientists are now demonstrating that, indeed, there was some kind of wide-ranging, catastrophic flood which took place in the middle east back in ancient times. It was this flood that lies behind the story of Noah's Ark. As Judaism does so well, the authors of the story of Noah's Ark sought to place the catastrophic flood in some kind of theological context, in the context of God's redemptive plan for the world.

Implicit in this story is the idea that God makes mistakes. Perhaps even more delicious is God's inability to correct mistakes. For surely, the post-flood world doesn't look any better than the pre-flood world, does it? We humans still can't follow directions. Siblings continue to kill one another. God's attempts to correct mistakes were as ineffectual as our efforts to correct our mistakes.

In a very real way, our generation's efforts in the area of genetics resembles the events captured in the story of the Great Flood. Genetic engineering is nothing less than an attempt to re-create the world. Like the story of the flood, dissatisfied with humanity as it is, we hope to create a new, improved, superior humanity. By tinkering with the genes, fiddling with alleles, we hope to do what Jesus commanded us to do. We will give sight to the blind, make the paralyzed walk, exorcize the demons which plague the lives of the mentally ill, eliminate disabilities which make learning difficult, and so much more.

In many ways, what is unfolding in the area of genetic science is very exciting. Recent experiments resulted in blind dogs regaining their vision. This success has filled blind people across the world with hope that one day they will be able to see a sunset, a rose, and, most importantly, the faces of their children, spouses, parents. In like manner, it appears that a terrible disease like Huntington's Disease can be eliminated with a rather contained, discrete genetic change which does not have a ripple affect across the whole genetic structure of a person.

In a fascinating way, genetic discoveries are affirming some of Christianity's most fundamental and important beliefs. For example, research on DNA reveals that each and every person is absolutely unique, totally special. There is no person exactly like another person. This is no longer a theological assertion. It is a scientific fact, used in courtrooms around the world.

The science of DNA also teaches us that each and every person is inexorably and inseparably linked to the past. We are a product of all that has come before us. The individual is produced by the whole. There are no "self-made" men or women.

Genetics also teaches us that disease is a deviation from the norm. For example, sickle cell anemia is an unhealthy mutation which took place when West African bodies successfully immunized themselves against malaria. Breast cancer results from a dominant gene that appears in some but not all individuals. Genetics thus verifies our theological assertions over the ages that God desires us to be healthy, that health is God's norm for us, that the quest for health is built into our makeup.

However, genetic engineering also raises profound and troubling questions. This new technology puts power and possibilities in human hands which previously were held only by nature. For example, one day we will be able to choose the gender of our child. We will be able to choose the intelligence level of a child. We will be able to rid a child of an enormous number of problems ranging from dyslexia to diabetes. In other words, we will be able to create the child we want rather than give birth to the surprising child we receive today.

Putting all of this power in the hands of humans terrifies some of us. Many people of faith, in particular, have objected that we are assuming God-like authority and power. They say, "Stop now. Stop the science before it is too late."

As I see it, such a demand is not only unreasonable. It is also impossible. Science cannot be stopped. The church has tried to stop scientific progress in the past. And we have failed. If we try to stop the science of genetics today, we will fail again.

If work on genetics is not carried out in the public realm, it will be carried out in the private sector or go underground. If an individual will spend \$20 million for a few days in space, what will some rich person spend to set up a genetic engineering lab to create a "perfect human"? Or more sympathetically, what billionaire wouldn't spend a huge junk of her fortune to sponsor research that might restore the sight of her child?

We are nothing less than fools if we think we can stop genetic engineering by banning certain scientific research. There is no stopping the intellectual process of discovery which is taking place in genetics labs around the world. The only question, indeed, THE question for Christians and other people of faith must be: "What do we do with this science? How do we use it? Do we use it?"

As Paul said to the Corinthians, the mere fact that one can do something doesn't make it right to do it. We are free to say "no" to life's options as well as "yes." The fact that heroin exists doesn't mean we should inject it in our veins. The fact that we can kill people legally does not make the death penalty morally acceptable. The fact that we have a nuclear bomb doesn't mean it is right to use it.

God gives us a brain, a conscience, and the ability to reason morally so that we can choose between what is good for us (and everyone else) and what is not. In the future, genetic engineering will create options for us that we don't presently possess. However, merely possessing the options does not mean that we should use the options.

Of one thing, we can be sure. The increased options created by genetic science will make life more complex. Our moral choices will increase exponentially in number and be disturbing in nature. As a result, people of faith will be challenged in new ways.

Starting today, as Christians, you and I have to listen and learn about genetics. We need to know what a double helix does as surely as we know what a cancer cell does. Science is way ahead of most of us in the church right now. You and I need to play catch up and we need to play it quickly.

I hope that sometime in the fall or winter we can organize a Saturday morning education event centered on genetic engineering. We have fabulous resources in this city. The Human

Genome Project is located here. Washington is at the epicenter of the genetic engineering revolution. We need to bring some of these folks down here and learn from them.

Once we learn the basics about genetics, the hard work will really begin. How do we use this knowledge? Who controls it? Should it be public or private? What, if any, restraints will we place on the implementation of genetic technology? Will this technology be made available to everyone or will only the wealthy be able to use it?

As the conversation deepens, someone will inevitably say, "But aren't we playing God? We have no right to make these kinds of decisions." Let me address that concern for a moment. It is an important sentiment

Fact of the matter is, you and I play God all the time. We play God when we allow our drug companies to keep AIDS-related drugs at such a high price that most of the world can't afford them. We play God when we declare that drug addiction is a crime and lock people up for years as punishment although we say that alcohol addiction is not a crime deserving jail time. We play God when we devote billions of dollars on over-priced military hardware while millions live in abject poverty in Rwanda, the Congo and elsewhere in Africa. Parts of the church play God when they declare Christians to be saved and Jews, Muslims and everyone else to be damned.

On a more personal level, we play God when we turn off life support systems (or maybe we stop playing God when we turn them off). We play God when we have the amniocentesis test and then make decisions based on the result of the test. We play God when we get divorced, ignoring the statement "what God has put together let no human put asunder."

So we are playing God all the time, you and I. The only thing more dangerous than playing God is not understanding that we play God. It is part of life. It is inevitable. We make God-like choices all the time.

What should concern us is not whether or not we are playing God. What should concern us is whether or not we are playing God well. Are we playing God gracefully or disgracefully? Are we acting in God's image or society's image?

As some of you know, I come from a long line of ministers. My great grandfather, grandfather and four great uncles, father, and two cousins all were or are in the ministry with another one on the launching pad at Princeton Seminary. As I listened to a geneticist talk several weeks ago, I started to wonder, "Is there a Presbyterian minister gene? Can this explain the Wimberly assault on the church?"

On a more serious note, genetics certainly explains a history of chronic depression that I have traced back through my family line. There were a significant number of my ancestors who struggled with depression. Some of them drank too much as well, probably as a means of self-medicating their depression.

I have dodged the depression and alcoholism bullets. However, would I want that gene for depression removed from my family? It caused so much pain and suffering for my ancestors. And yet, if it was removed, would I be who I am today? After all, we are a product not just of our genes but the family systems in which those genes exist. Would I have the same empathy for people who struggle in life? Would my ancestors have been who they were, a group of troubled but terrific individuals of whom I am very proud.

A huge number of artists are dyslexics, many others are bipolar. Will we dampen the creative power of our species if we make everyone "normal"? And who defines what is "normal"? Would Jackson Pollack have painted his work if he was "normal"?

Many disabled people have developed enormous personal strength coping with their disability. They have then used that strength to make huge contributions to society. What do we lose if everyone is “healthy”? And who defines “health”?

Questions, questions and more questions. This rapidly developing science of genetics forces us to ask questions about who we are that can make us pretty uncomfortable. However, if we consider these questions of identity within our larger, overall identity as God’s children, we have nothing to fear, nothing to lose. When we ask who we are within the context of those we are, we can only end up in a redemptive place.

Genetic engineering will not create a “better world” any more than the flood created a better world with the mythical remnants from Noah’s ark. After all, as Christians, our goal is not to better. Our goal is to be faithful. If we remain true to that goal, we need fear neither floods nor genetic engineering.

Let us pray: Gracious God, Jesus called the meek blessed. Dare we edit meekness out of the genetic code? It is a profound question, one which draws us deeper into the mystery of our humanity and your divinity. Help us to be unafraid to travel where none of our ancestors traveled, to know things none of our ancestors knew. For if our heart is faithful, our spirit hopeful and our actions loving, we need fear nothing, not the valley of the shadow of death or the specter of genetic research.

References

¹ Statement for the Congressional Record, October 21, 1987.

² Oates 1974: 11.

³ Oates 1974: 11.

⁴ This summary follows Oates 1974: 10-25. The specific formulation of the pastoral blessing given here is that of Paul Pruyser and Myron Madden.

⁵ Interview with the Catholic Health Association, Health Progress September-October 1999:23.