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Ethics and the New Genetics Task Force

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intermediaries, signed an agreement in May 2002. NCCA has helped EJLC find new loan applicants while improving its ability to assess applicants and its whole program.

During the triennium, EJLC reviewed and acted on loan applications. Six loans totaling $1.4 million were dispersed, including one to the Diocese of Atlanta for affordable housing. Another two loans totaling $550,000 have been approved but not yet dispersed, and a number of other loan applications are in the pipeline. The entire economic justice loan portfolio includes $5.6 million in loans outstanding to 25 different institutions, with an additional $1.5 million available as of January 1, 2003 for investment.

During the remainder of the current and into the next triennium, EJLC hopes to improve communication with parishes, dioceses and Church institutions to increase the effectiveness of its work, as it seeks increased Episcopal Church involvement in this important ministry.

ETHICS AND THE NEW GENETICS TASK FORCE

www.episcopalchurch.org/gc/ec/ccs/eceng/default.html

Membership

Mr. David H. Smith, PhD, *Chair*	Indianapolis
The Rev. David Ames	Rhode Island
Ms. Mary Anderlik, JD, PhD	Kentucky
Ms. Cynthia Cohen, PhD, JD	Washington
The Rt. Rev. Theodore Daniels	Virgin Islands
The Rev. Lindon Eaves, PhD	Virginia
Ms. Elizabeth Heitman, PhD	Texas
The Rev. Jan Heller, PhD	Olympia
Mr. Bruce Jennings, MA	New York
The Very Rev. James Lemler	Chicago
Mr. Timothy Sedgwick, PhD	Virginia
Mr. LeRoy Walters, PhD	Washington
Ms Mary White, PhD	Southern Ohio
Dr. Ellen Wright Clayton, JD	Tennessee

WORK SUMMARY

The Task Force on Ethics and the New Genetics was created by the Executive Council after General Convention 2000 to address concerns raised by the new genetics. Its work, *A Christian Response to our Genetic Powers*, will be distributed at General Convention. Rowman and Littlefield will publish and *Anglican Theological Review* will receive royalties. Possibilities that get us started include:

- Genetic information can inform decisions on whether to have children.
- Genetic testing on adults or children may reveal surprising information on the individual and others.
- Embryos and fetuses may be tested for specific genetic traits**.**
- Genes of humans or embryos may possibly be "improved," thus shaping the individual's biology.
- Genetic knowledge may be used to deny employment or health insurance.

These possibilities raise concerns for the whole Church. Moral teaching is a first concern. The church must listen, study and share its wisdom. The second concern is pastoral. Improving human lives is balanced by the possibility of abuse and injustice. Anticipating problems may enable thoughtful preparation but still tax counseling and liturgical resources.

New genetic knowledge raises theological issues. For example, the roles of fate and choice seem to be changing, as phenomena once deemed beyond human control become controllable. A genetic misfortune once seen as bad luck may now be considered someone's fault. For example, a parent or a physician who did not run a test might be blamed.

No Task Force can give definitive answers to these ethical and theological issues. Our goal is to encourage a continuing dialogue as we draw on our Anglican tradition in addressing them.

Theological Perspectives

Genetic research should be celebrated. Awe and wonder increases the more we know about God's creation. Genetic knowledge lets us help each other when things go awry. Alas, our knowledge may be used incorrectly. Three metaphors in scripture and tradition structure our use of genetic knowledge.

First, is the metaphor that humans are made in God's image. We work with God to bring about good. Theological traditions have diversely interpreted this metaphor. For us, being made in God's image suggests responsibility for God's creation as we treat humans with something like the respect due God.

Life as a gift from God is the second metaphor; it is gratuitous that we exist. This metaphor is misused when it implies that all misfortunes, including genetic ones, are simply crosses to bear. Yes, God's handiwork is in all things; the mistake is thinking that acceptance is the only response. If this is true no medical care is ever appropriate! Our stewardship of God's creation is to prayerfully discern what to celebrate, let go or change.

A third metaphor refers to family life. We speak of the "household of God" and "children of God." These suggest the importance of virtues such as love, hope and thankfulness. Attention shifts from "What is OK for me to do?" to the needs of others.

These convictions lead us to three basic points. "Playing God" is a criticism often made of using our new genetic powers. We reject this charge. Yet we live in a world too broken to allow us to assume that using genetic knowledge or technology will always come out right.

A second important issue is suffering and God's love. The genetic lottery is unfair. Genetic problems are not the fault of ill or troubled persons, their parents, or any identifiable human group. Guilt or blame has no place in the distribution of genetic abnormalities. Misfortune may offer spiritual growth but there is no correlation between it and a human's spiritual needs. We can find help in trusting God and in Christ's identification with us in suffering and death.

Genetic Testing

Since our understanding of genetics is still in its relative infancy, what we know is constantly changing. As a result, the diagnostic or predictive value of many genetic tests is uncertain. Further, genetic test results have implications for the blood relatives of the person tested, which raises new questions of responsibility and confidentiality within families.

Prenatal testing is offered to women at high risk of having a child with abnormalities such as trisomy 21 or Down syndrome. No therapy exists for these defects. Prenatal testing is ethically controversial since a parent may terminate a pregnancy because of test results. This can invoke, for example, the abortion debate, the disability critique, "playing God," commodification of children, new parental responsibilities, and eugenics.

Postnatal testing, which comes in many forms, including newborn screening (the most common form of genetic testing), testing of children and adolescents, and adult testing, raises questions about *when* testing is appropriate. Other issues include whether individuals have a duty to be tested, a right to refuse testing and a right not to have test results disclosed to third parties including relatives.

The history of eugenic practices and policies of the last century, and the problem of abuse of power are serious causes for worry. The problems are different, however in a culture that focuses on the liberty of the individual. Additional knowledge may be liberating. It also may become a basis of ill informed discrimination in employment, a ground for loss of health insurance, and an occasion for conflict within families. We defend human dignity in the face of social pressures and stress increased attention to informed counsel and communal support.

Gene Transfer for Therapy or Enhancement

Our growing capacity to introduce, delete, and change genes in human's promises to impact our lives and our descendants. The prevention of gene-linked disease is one possible goal of treatment and another may be to improve humans. Two sorts of interventions might be possible because of our new genetic powers. These interventions are:

- Somatic cell interventions that introduce genes into the non-reproductive cells of the human body**.**
- Germline interventions that target genes in the early embryo.

We conclude that somatic cell gene therapy, if rendered safe and effective, would be morally acceptable to use in humans. Research into somatic cell therapy must be governed by strict adherence to ethical standards of research. Germline gene therapy would also be morally acceptable, in principle, but research into such interventions should not be undertaken until safety precautions are developed that account for the welfare of future generations, and until there has been greater public discussion of the ethical and social issues that they raise. We urge that a public body be appointed to oversee all research and clinical use of these genetic interventions.

Creating and Shaping Children

We turn to the union of new genetic capabilities with new reproductive technologies, exploring the historic and contemporary meanings of procreation and of parenthood. We stress both the companionate and procreative ends of our God-given sexuality. We continue a persuasive historic bias for describing children as a gift. Christian parents are called to rear children with love and care, mindful of the integrity, dignity and value of each child. We note the tension between accepting children as they come to us and seeking to alter them for their good or our own.

In this context**,** we consider interventions that raise ethical and theological concerns:

- *In vitro* fertilization (IVF) is needed for several of them, and we conclude that it is a morally acceptable way to overcome fertility barriers if parents and health professionals are mindful of its dangers.
- Three procreative interventions dependent on IVF can be used to avoid serious genetic disease in children: gamete donation, pre-implantation genetic diagnosis (PGD), and germline interventions. Gamete donation is use of sperm or egg from someone other than the couple to have a child. Pre-implantation genetic diagnosis (PGD) involves the selection of some embryos for implantation and the discard of others with genes associated with serious disease. Germline interventions involve repairing or changing genes in early embryos that would then be transferred to a woman's body to develop into children.
- We argue that both gamete donation and PGD are morally acceptable ways of averting genetic disease in future children even as they raise a need for moral caution. We are uneasy ethically about using germline interventions to overcome genetic disease in future children both because of serious risk to the future child and the further risk of excessive parental control or manipulation to specify the characteristics of their future children.
- Reproductive cloning, a fourth intervention that might be used to address serious disease in future children, is not morally acceptable at this time as it endangers the safety of children who might be conceived and threatens their dignity as unique individuals. Its use departs from accepted social and ethical values.

We are convinced that using new technology to avert genetic disease in children should be guided by the purpose of seeking good for them in a responsible and just manner. A commitment to the good of children may lead to public policies that limit choices for adults.

The Moral Status of Human Embryos and the New Genetics

We consider the question of the moral status of the early embryo in light of scripture, the Christian tradition, recent discoveries in embryology, and contemporary thought. Although scripture provides no explicit discussion of this question, it deeply values human life as it is being made. The Church Fathers distinguished between "unformed" and "formed" human life, viewing the latter, but not the former as potentially human. To

end "unformed" embryonic life was considered to violate the procreative end of sexual relations; to end "formed" embryonic or fetal life was considered morally more serious and akin to homicide.

We conclude that early embryos before 14 days do not have the same moral status as living humans but that they are owed moral consideration since approximately 20 percent of them might avoid miscarriage (80% of them are lost before implantation) and go on to become humans. Moreover, the best work in embryology suggests that the embryo isn't a stable individual until approximately 14 days after fertilization. The question of using these embryos is different from the issue in abortion: the earliest embryo is a different *kind* of entity than the later fetus, and poses no risks to its genetic mother since it has not implanted. "Moral consideration" means that early embryos are owed appropriate care, respect and protection, but that there can be moral justification for not transferring an early embryo to a woman's body.

Our view, in principle, would allow pre-implantation genetic diagnosis to be used to implement decisions against transferring affected early embryos in order to avoid serious genetic disease in future children. Since germline interventions would be employed to treat early embryos with disease-linked genes, the use of these interventions, if safe and efficacious, would show moral consideration for the early embryo and future children.

Economics and Politics of the New Genetics

We return to the economics and politics shaping the choices offered by the new genetics. Science is prompting individuals, families, and health professionals and legislators to raise questions about the uses, patenting, and sale of genetically altered genes and DNA sequences. We weigh the contention that existing law and policy endanger respect for life by treating it simply as a commodity to be bought or sold.

Morally adequate answers are elusive but the metaphor of stewardship illuminates debate over appropriate paths for development of products and services based on genetic research. This perspective links the patenting debate to a larger discussion concerning the norms of science versus commerce, the relationship between public and private genetic endeavors, and the sufficiency of oversight of controversial areas of research. The question of who should benefit from investment in research needs to be informed by considerations of justice, and by attention to those on the margins of society and who lack basic health care.

Church action

How can the Church participate in the dialogue while providing appropriate leadership and raising critical questions about genetic issues? The Episcopal Church's role includes education, pastoral care and advocacy for those who suffer from genetic and other disease. To be effective ministers we need a solid education about genetic issues and we must speak for a just allocation of resources in health care.

Christian education programs, including those for children and teens, should share how we differ due to our genetic make-up while emphasizing that all are loved by God and each is a child of God. Adult education programs should engage questions about genetics so that people can: 1) gain current and useful information about genetics; 2) relate compassionately to people with a genetic disease, or who are struggling with genetic testing and diagnosis decisions; and 3) identify and refer anyone who would benefit from genetics counseling and services.

Education programs at the diocesan, provincial, or seminary levels might develop collaborative relationships with other disciplines, institutions and communities of faith to further their expertise in offering pastoral care for families and individuals with genetic disease.

Pastoral care related to genetics begins with pre-marital counseling and continues with a child's birth until death. Conditions related to genetics can occur at any time in a life. Some pastoral care topics are:

- Questions about conception, carrier testing prior to pregnancy, prenatal care and diagnosis.
- Problems with infertility, including in-vitro fertilization, adoption, surrogate parenting.
- The possible need for neonatal intensive care, support for the "new" family and child care.

Finally, the Church has an advocacy role. Public policy issues of justice, equality and access to appropriate health care and adequate insurance are paramount in assuring the safety and well-being of every person. Christians**,** along with other religious bodies and secular organizations**,** can support legislation to assure high quality care for individuals and families through genetic screening, testing, and disease management.

Resolution A011 Ethical Guidelines for Gene Transfer and Germline Interventions

Resolved, the House of ____ concurring, That the 74th General Convention recognizes that God has entrusted us to use our medical and other capabilities to work toward healing and restoring creation where it has gone awry. Therefore, this General Convention sets forth the following guidelines for genetic research and interventions:

- It is morally acceptable, in principle, to engage in experimental somatic cell human gene transfer for therapeutic purposes, in an effort to treat or prevent disease.
- All experimental genetic interventions in human beings must meet ethical standards of research, which require that investigators demonstrate the scientific merit of their research, protect the health and welfare of human volunteers, while ensuring their voluntary choice to participate.
- Until there is strong scientific evidence that the use of germline procedures is safe, effective**,** and stable across generations and that guidelines have been established for their use before they are employed, we should not consider the use of germline interventions in human beings.
- Ongoing public oversight of research into both somatic cell and germline interventions, in both the public and private sectors, is essential. Members of a federally appointed interdisciplinary review body should be chosen by publicly accountable methods.

EXPLANATION

As stewards of creation, we are called to help mend and renew the world in many ways. It is in keeping with God's loving and healing purposes to carry out research into the use of somatic cell (non-reproductive) genetic interventions that might treat and prevent serious disease. However, such gene transfer has not yet been proven safe and effective for general use in human beings Likewise, we are not at a point where it would be safe to engage in research into germline interventions, nor have we given adequate public reflection to the ethical and social import of doing so.

The need for careful oversight of research into both somatic cell and germline interventions and for public discussion of the ethical, theological, and policy issues raised by the possibility of using germline interventions in humans is currently being addressed only to a limited degree. Until recently, the Recombinant DNA Advisory Committee (RAC) of the National Institutes of Health, had authority to review federally funded research protocols involving recombinant DNA, as well as private sector protocols sent to it voluntarily. We recommend that the re-empowered RAC be placed under the aegis of a federal agency, such as the Department of Health and Human Services, that is independent of those federal agencies that directly fund biomedical research.

Resolution A012 Caring for Children in the Face of the New Genetics

Resolved, the House of ____ concurring, That the 74th General Convention reaffirms the church's traditional teaching about parenting and that children are trusts and gifts from God to be nurtured toward maturity**.** Therefore:

- Genetic testing of children can be an important part of parental responsibility, and may be carried out if it is clearly in the child's best interests to be tested.
- Parents should make responsible use of medical services, including treatment for genetic diseases and the use of somatic gene transfer therapies if they should be proven safe and effective.
- New genetic techniques may be used in conjunction with *in vitro* fertilization to avoid procreation of human beings with clearly serious disorders of their DNA or chromosomes.
- It is not morally acceptable to use reproductive cloning at this time for any reason, because the technique constitutes an unsafe form of experimentation on children. It is therefore morally irresponsible for physicians, scientists, and prospective parents to engage in it.

EXPLANATION

Our rapidly expanding genetic capabilities and our highly sophisticated new technologies for reproduction offer parents and medical providers powerful tools with which to address genetically based problems in our children. This novel genetic and reproductive power is a gift from God to be used for the benefit of children with the intent of healing. It should not be used to fashion children according to their parents' unique personal ambitions or in ways that unduly deny children freedom of choice when they mature.

The hope of becoming parents of children who are free of disease-linked genes should not be fulfilled by using novel reproductive measures that endanger the safety of the resulting children. Germline genetic alteration is not intrinsically wrong, but attempts genetically to modify our children when carried out solely to give parents great control over the biological properties and personality traits of their offspring, are morally questionable, for they challenge the individual integrity, dignity, and value of the child. Reproductive cloning endangers the safety of the resulting children and puts important ethical and social values at risk. Those who hope to be parents but who are at risk of having children with serious genetic disease should consider using other measures, such as adoption, to have children.

Resolution A013 The Church's Role in Counseling and Education on Biomedical Ethics

Resolved, the House of _____ concurring, That the 74th General Convention, recognizing the changing world in which we live, continue a program of sustained study in bioethics to inform and educate members of congregations and clergy about the expanding range of issues and choices they and their children will face throughout life. To this end, we commend study of *A Christian Response to our New Genetic Powers*; and be it further

Resolved, That the Church:

- Call on Provinces and Dioceses to work with congregations to encourage local education and to provide resource teams**.**
- Devise a way to sustain initiative and development of expertise in biomedical ethics in the national church through the continued work of an Executive Council Task Force with a budget of $36,000 for the triennium.
- Stress the importance of basic education about science and biomedicine among the people of God and encourage and support the teaching of biomedical ethics in its seminaries.
- Commit itself to ecumenical and interfaith discussion of questions of biomedical ethics and be prepared to join with other groups in such interfaith educational ventures.

EXPLANATION

Bioethics is the study of the social, ethical and spiritual questions arising from expanding knowledge and technological possibilities in medicine and the life sciences. It addresses issues of and professional practice in health care, public policy regarding the uses of biotechnology, business enterprise in the area of health care, and many other areas of importance to our life together. The questions of biomedical ethics directly impact on issues of life and death, birth and aging that human beings face. Education is essential if the church as a whole is to be prepared to offer informed counsel. Church leaders must know when to consult with or refer to persons with relevant expertise when dealing with issues of genetic testing and intervention, uses of new reproductive technologies, and the prospect or reality of death. We should use or develop liturgical forms that will help patients and professionals who are rejoicing, worried or sorrowful.

Resolution A014 Approve Research on Human Stem Cells

Resolved, the House of _____ concurring, That the 74th General Convention supports the choice of those who wish to donate their early embryos, remaining after *in vitro* fertilization (IVF) procedures have ended, for embryonic stem cell research, and urges the United States Congress to pass legislation that would authorize federally funded research for the derivation and use of human stem cells from early embryos that have been donated for such research by those who have completed IVF procedures, provided that:

- these early embryos are no longer required for procreation by those donating them;
- those donating early embryos have given their prior informed consent to their use in stem cell research;

- directors of fertility clinics from which early embryos are obtained certify that they were not deliberately created for research; and
- directors of fertility clinics and stem cell investigators certify that such early embryos have not been obtained through sale or purchase; and be it further

Resolved, That the 74th General Convention urge the Secretary of Health and Human Services to establish an interdisciplinary oversight body for all research in both the public and private sectors that involves stem cells from human embryos, parthenotes, sperm cells, or egg cells and have this body in place within six months of passing such legislation.

EXPLANATION

In recent years, biomedical investigators have explored the possibility that the use of human stem cells might be effective in treating such diseases as Alzheimer's, Parkinson's, stroke, cardiovascular disease, diabetes, and spinal cord injuries. The use of these cells might also provide an alternative to organ transplantation. Stem cell investigators have therefore begun to carry out research involving both adult human stem cells and early human embryonic stem cells at the blastocyst stage (five days after fertilization).

Ethical concerns have been raised about whether this research should use stem cells that have been derived from early human embryos. Episcopalians generally recognize that early embryos are owed special moral consideration. For some this is because they are already persons in the eyes of God; for others the fact that embryos may mature and be born as children makes them special.

Even before stem cell research became a scientific possibility, the use of the new reproductive technologies required the creation of early human embryos. Early embryos have been developed at fertility clinics in conjunction with the use of *in vitro* fertilization (IVF) to assist persons who face physical barriers to procreation. At most infertility clinics, several embryos are created at one time during the IVF procedure to ensure that there will be a sufficient number available for later attempts at implantation should the first try prove unsuccessful. We have acknowledged and accepted this as a society and as a church body. Two resolutions of the General Convention have also approved the use of IVF by those who experience difficulties in having children *(GC Resolution -1982-A067 Approve the Use of "In Vitro" Fertilization and GC Resolution-1991-A101 Reaffirm the Recommendation Considering External Fertilization)*.

Early embryos remaining after IVF procedures have ended could morally be donated for embryonic stem cell research. The alternatives for couples who have completed their reproduction are to donate the embryos for research, to donate the embryos to other couples, to discard the embryos, or to preserve them as long as possible. Most couples prefer not to donate remaining embryos to other couples, and indefinite preservation simply postpones the inevitable. Thus the two remaining alternatives are to discard the embryos or to donate them for research. If these embryos are donated for stem cell investigations, they could assist promising research that might enable those who are seriously ill with little hope of recovery to be healed.