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Christian Reflections on the Genetic Revolution

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On June 26, 2000, Francis Collins and J. Craig Venter were at the White House to join President Clinton for the historic announcement that some ninety percent of the human genome had been mapped, completing the first stage of the Human Genome Project ahead of schedule. President Clinton declared that 'Today, we are learning the language in which God created life'. David Gushee, a Christian ethicist, commented that humanity '… will spend much of the 21st century attempting to speak that language … Christians must participate in the international conversation about these changes before they become irreversible.'[1]

This article is an attempt to contribute to that conversation on the ethical implications of genetic research and technologies. After briefly surveying developments in genetics from Mendel to the Human Genome Project, key issues and concepts will be identified, and a biblical-theological framework for Christian ethical reflection will be outlined. It will then be argued that this framework can serve as a suitable starting point for ethical analysis of issues in this area such as genetic testing, genetic therapies, human enhancement, and cloning.

The Science of Genetics: Historical Background

The pioneering discoveries of Gregor Mendel in the 1860s mark the birth of the modern study of genetics, but even in ancient times plant and animal breeders had observed patterns of inheritance and variation and attempted to produce favourable varieties through guided selection. In ancient Greece, Aristotle speculated on the nature of inheritance and animal reproduction. It was only in the seven-

1 David P. Gushee, 'A Matter of Life and Death: The Biotech Revolution', *Christian Ethics Today* 8:3 (June 2002), pp. 13-17 at 13.

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teenth century, however, that sexual reproduction in plants was confirmed, and it was not until 1838 that the cell was known to be the basic constituent of all living organisms.[2] In his landmark publication of 1859, *On the Origin of Species by Means of Natural Selection*, Darwin proposed random variation and natural selection as the keys to the formation of new species, but the genetic basis of this process was as yet unknown.

In 1865 Gregor Mendel, who had studied physics before joining an Augustinian monastery in Brunn, Moravia,[3] published in an obscure journal his seminal paper, 'Experiments on Plant Hybrids.' Mendel practised botany in the garden of the monastery and in his experiments with peas demonstrated how seven traits varied in mathematically predictable ways. Mendel hypothesized that discrete units of inheritance that he called 'factors' did not blend during fertilization. His theory of 'particulate' inheritance broke with traditional ideas of 'blending' inheritance and laid the foundations for the modern concept of the gene.

Mendel's research remained unknown and neglected until it was independently rediscovered around the turn of the century by the biologists Hugo deVries, Carl Correns, and Erik von Tschermak. In 1902 Walter Sutton proposed that the units of heredity were to be found on the chromosomes of the cells. In 1906 William Bateson, who coined the term 'gene', discovered the principle of linkage, in which several factors were located on the same chromosome and moved together as units.[4]

In the years prior to the First World War, T.H. Morgan and his graduate students at Columbia University conducted extensive breeding experiments with the fruit fly *Drosophila melanogaster.* Morgan's 1926 book, *The Theory of the Gene,* proved to be a landmark in the field and helped to bring about the widespread acceptance of Mendelian principles of heredity.

In 1927 one of Morgan's associates, H.J. Muller, demonstrated that exposure to X-rays could induce mutations in fruit flies. This work, for which Muller received the Nobel prize, was to assume great public policy significance in the years subsequent to the dropping of the atomic bomb on Hiroshima and Nagasaki, when citizen concern for the harmful effects of radiation became heightened.

The eugenics movement that

2 Material in this section has been adapted from the author's article 'Human Enhancement Genetic Engineering and the Image of God,' in John and Paul Feinberg, eds., *Foundational Issues in Ethics* (Wheaton, IL: CrossWay Books, forthcoming). On the history of genetics, see also L.C. Dunn, *A Short History of Genetics* (New York: McGraw-Hill, 1965); A.H. Sturtevant, *A History of Genetics* (New York: Harper and Row, 1965; David Suzuki and Peter Knudston, *Genetics: the Clash Between the New Genetics and Human Values* (Cambridge, MA: Harvard University Press, 1989), pp. 44ff.

3 Eric S. Lander and Robert A. Weinberg, 'Genomics: Journey to the Center of Biology', <www.britannica.com/bcom/original/article/print/0,5749,4701,00.html>

4 George W. Burns and Paul J. Bottino, *The Science of Genetics*, 6th ed. (New York: Macmillan, 1989), p. 3.

emerged during the twentieth century represents one of the darker aspects of the history of genetics. The term 'eugenics' had been coined in 1883 by Francis Galton, a cousin of Charles Darwin. Galton understood the task of eugenics to be improving the human race by allowing 'the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable.'[5] The history of the eugenics movement in America and Germany was to show that this 'science' could in fact become a tragic blending of pseudo-scientific ideas and racial prejudices imposed by the force of law on the socially disadvantaged.

In 1907 Indiana became the first state in America to pass a compulsory sterilization law, authorizing the forcible sterilization of the inmates of state institutions that were considered to be insane, 'feeble-minded', idiotic, or who were convicted rapists or criminals, as determined by a board of experts.[6] Between 1907 and 1937 some thirty-two states had passed sterilization laws, and by 1958 some 60,000 sterilizations had been performed in the United States.[7]

In its now infamous decision of 1927, the U.S. Supreme Court in *Buck v. Bell* upheld a 1924 Virginia law that permitted the involuntary sterilization of the inmates of state institutions who were believed to be 'defective persons' whose reproduction represented a 'menace to society'.[8] Justice Oliver Wendell Holmes, writing for the majority, declared that the principle that justified compulsory vaccination was broad enough to justify ' … cutting the fallopian tubes … Three generations of imbeciles are enough.'[9]

In 1924 the U.S. Congress passed the Immigration Restriction Act, limiting immigration from countries in eastern and southern Europe. This law reflected influence of Charles Davenport and other activists in the eugenics movement, who believed in the superiority of the 'Nordic' races from northern Europe, and who believed that the vitality of the American racial stock was being weakened by the influx of the biologically inferior 'new' immigrants.[10]

The American sterilization laws were upheld as models in Nazi Germany. By the end of the Nazi era, some 350,000 forced sterilizations had been performed under the 1933 statute, the 'Law for the Protection of Genetically Diseased Offspring.' These forced sterilizations, based on pseudo-scientific

5 Cited in Ben Mitchell, 'Genetic Engineering - Bane or Blessing?' *Ethics and Medicine* 10:3 (1994), p. 51. On the history of the eugenics movement, see Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (New York: Alfred A. Knopf, 1985); Mark H. Haller, *Eugenics: Hereditarian Attitudes in American Thought* (New Brunswick, NJ: 1963, 1984); Kenneth M. Ludmerer, *Genetics and American Society* (Baltimore: Johns Hopkins University Press, 1972).

6 Ludmerer, *Genetics and American Society*, p. 92.

7 Haller, *Eugenics*, p. 141.

8 Paul Lombardo, 'Eugenic Sterilization Laws,' <www.eugenicsarchive.org/html/eugenics/essay8text.html>

9 Cited in Henry Steele Commager and Milton Cantor, eds., *Documents of American History*, v.II, 10th edition (Englewood Cliffs, NJ: Prentice-Hall, 1988), pp. 216-217.

10 Ludmerer, *Genetics and American Society*., p. 96.

ideas of 'racial hygiene,' set the stage for the German euthanasia movement and eventually, for the Nazi extermination of six million Jews.[11]

The year 1953 saw the landmark discovery of the double-helical structure of the DNA molecule by Francis Crick and James Watson.[12] By 1966 DNA's complete coding sequence had been deciphered, in which the pairing of the amino acids Adenine (A) with Thymine (T) and Guanine (G) with Cytosine (C) on opposite sides of the strand explained how genetic information could be copied and how mutations could arise through imperfections in the copying process.[13]

In 1972 the first recombinant DNA molecules were synthesized in the laboratory, and in 1980 the Supreme Court ruled in *Diamond v. Chakrabarty* that a genetically modified organism could be patented. The U.S. Patent Office awarded a General Electric scientist a patent for an oil-eating bacterium that could help clean up oil spills.[14] In 1982 human insulin was synthesized through recombinant DNA technology, and in 1990 researchers at the National Institutes of Health performed the first sanctioned gene therapy trials, treating four-year old Ashanti DeSilva for a rare genetic disease called severe combined immune deficiency (SCID).[15]

1990 also marked the launching of the Human Genome Project, the largest collaborative project in the history of biological research.[16] Advances in computer technology and automated DNA-sequencing devices enabled the project to proceed faster than scheduled. On June 26, 2000 Francis Collins and J. Craig Venter joined President Clinton at the White House to announce that a first draft of the human genome had been completed, mapping some 90 percent of the approximately 3 billion base pairs that are contained in every human cell. The president remarked, 'Today, we are learning the language in which God created life.'[17]

11 Robert Proctor, *Racial Hygiene:Medicine Under the Nazis* (Cambridge, MA: Harvard University Press, 1988), pp. 95ff.

12 The original article is J.D. Watson and F.H.C. Crick, 'Molecular Structure of Nucleic Acids,' *Nature* 171: 4356 (April 25, 1953) 737-38. The story of the discovery is told in James D. Watson, *The Double Helix* (New York: Athenaeum, 1968).

13 Lander, 'Genomics: Journey to the Center of Biology'; Jerry Bergman, 'How Genes Manufacture Plants and Animals,' *CEN Tech. Journal* 11:2 (1997), pp. 204-6, 'The Structure of DNA.'

14 Robert N. Proctor, 'Genomics and Eugenics: How Fair Is the Comparison?' in George Annos and Sherman Elias, eds., *Gene Mapping: Using Law and Ethics as Guides* (New York: Oxford University Press, 1992), p. 69.

15 'Human Gene Therapy,' National Reference Center for Bioethics Literature, Georgetown University, <www.georgetown.edu/research/nrcbl/scopenotes/sn24.html>

16 For background on the Human Genome Project see Carina Dennis and Richard Gallagher, eds., *The Human Genome* (New York: Nature/Palgrave, 2001); Thomas F. Lee, *The Human Genome Project* (New York: Plenum Press, 1990).

17 Quoted in David P. Gushee, 'A Matter of Life and Death,' *Christian Ethics Today* 8:3 (June 2002), p. 13. The original report of the scientific consortium is found in International Human Genome Sequencing Consortium, 'Initial Sequencing and Analysis of the Human Genome,' *Nature* 409 (2001), pp. 860-921.

The Issues and the Terminology

The term 'genetic engineering' is now used somewhat broadly to refer to a number of techniques used to measure or modify the genetic characteristics of a living organism.[18] One of the earliest occurrences of the term appeared in a 1969 editorial in the *New Scientist,* which stated that the day '... may be approaching when genetic engineering may make it possible to make a plant to order.'[19] The term 'genetics,' referring to the scientific study of heredity and variation, was coined by the biologist William Bateson in 1905.[20] W. Johannsen proposed the term 'gene' in 1911 to refer to the basic units of inheritance that had been studied by Mendel in the nineteenth century.[21]

For the purposes of this discussion, 'genetic engineering' is understood to refer to a range of interventions that would include the following: genetic testing and screening; genetic therapy; genetic enhancement; and cloning. *Genetic testing* and *screening* use various procedures to attempt to identify any one of a constantly growing number of genetically related disorders such as Downs syndrome, Tay-Sachs disease, haemophilia, Huntington's disease, cystic fibrosis, sickle-cell anaemia, PKU disorder, and many others.[22] *Genetic therapy* corrects or attempts to correct genetic defects in any of the cells of the body.[23] *Genetic*

18 The focus of this article is on *human* genetic interventions. For discussions of the ethical issues raised in relation to genetically modified crops, see David Magnus, 'Genetically Modified Organisms,' *Medical Ethics*, Spring 2001, pp. 1ff.; L.L. Wolfenbarger and P.R. Phifer, 'The Ecological Risks and Benefits of Genetically Engineered Plants,' *Science* 290 (December 15, 2000), pp. 2088-92; Barry Commoner, 'Unraveling the DNA Myth: The Spurious Foundations of Genetic Engineering,' *Harpers* 304: 1821 (February 2002) 39-47. Helpful background information on both genetically modified plants and animals is found in the article by Darryl Macer, 'Genetic Engineering in 1990,' *Science and Christian Belief* 2:1 (April 1990), pp. 25-40.

19 *New Scientist* 415 (August 28, 1969), p. 2, cited in R.W. Burchfield, ed., *A Supplement to the Oxford English Dictionary*, vol. I (Oxford: Clarendon Press, 1972), p. 1213.

20 Burchfield, *A Supplement to the Oxford English Dictionary*, p. 1213.

21 Burchfield, *Supplement*, p.1211. Bateson also coined the term 'genotype' to refer to the genetic constitution of an individual. 'Gene,' derived from the Greek genos, 'birth', is now understood to refer to a segment of DNA on a chromosome that codes for one or more proteins.

22 Genetic tests are performed on adults, children, newborn infants, and more recently, on pre-implantation human embryos. Genetic *screening* generally refers to the testing of a target population thought to be at risk for a particular disorder, e.g., people of African-American descent for sickle-cell anaemia, or Jews of eastern European origin for Tay-Sachs disorder. The online version of the standard reference work *Mendelian Inheritance in Man*, lists a continuously updated list of human genes and thousands of genetically related disorders: National Center for Biotechnology Information, Johns Hopkins University, www.ncbi.nim.nih.gov/Omim/

23 Various forms of genetic therapy can further be distinguished as 'somatic cell therapy,' which alter the somatic (body) cells but not the egg or sperm, and 'germ-line therapy,' which would modify the genetic composition of the egg or sperm, and so be transmitted to future generations.

enhancement would involve attempts to genetically modify an organism so as to improve a characteristic such as height, intelligence, memory, or lifespan. *Cloning* refers to the creation of one or more individuals with a genotype identical to that of the parent.[24] Each of these levels of genetic intervention, to be addressed below, raises its own set of ethical issues.

A Theological and Ethical Framework:

An evangelical approach to the ethical issues raised by the new genetic technologies will attempt to frame these questions within the larger context of biblical theology—the pattern of *creation, fall, redemption,* and the *new creation*—a movement that characterizes the overall sweep of God's redemptive action in history.[25] All of God's creation, including the human body, is *good* (Gen. 1:31; 1 Tim. 4:4) and as such is worthy of care and respect. Human beings occupy a unique place in creation, being made in the image and likeness of God (Gen. 1:26), and consequently human life has sacred value and is to be accorded the greatest care and protection (cf. Gen. 9:6), from the time of conception (cf. Ps. 139:13-16) onward.[26]

The biblical understanding of the created nature of man teaches that man is both 'spirit' and 'dust' (Gen. 2:7). As 'dust,' man shares with the lower creation a physical, chemical, and biological substrate that can be studied scientifically. As 'dust', humans share the same DNA-based genetic code that is common to life on earth. As 'spirit', however, man has a *spiritual* and *transcendent* nature that cannot be reduced to or completely understood in terms of physical, chemical, biological, or genetic categories alone. Biblical theology sees man not merely as a mechanism or object to be manipulated, but as a *morally responsible* personal agent whose personhood is adequately understood only in terms of a relationship to God.

Creation as man experiences it, however, is not in its original state, but *fallen* (Gen. 3:14-19) and imperfect, and subject to 'bondage and decay' (Rom. 8:20, 21). Birth defects, including those of genetic origin, can be understood in relation to this fallenness of creation (cf. Jn. 9:3). God's redemptive purpose in Jesus Christ is to heal the effects of sin and the curse

24 The ethical issues posed in the suggested distinction between so-called 'therapeutic cloning,' involving the creation and subsequent destruction of a (human) embryo in order to harvest its stem cells for research purposes, and 'reproductive cloning,' intended to eventuate in a live birth, will be addressed below in the section 'Ethical Analysis.

25 For discussions of this pattern of biblical theology, especially as it is developed in the Pauline corpus, see Herman Ridderbos, *Paul: an Outline of His Theology*, tr. John Richard De Witt (Grand Rapids, MI: William B. Eerdmans, 1975), and George Eldon Ladd, *A Theology of the New Testament* (Grand Rapids, MI: William B. Eerdmans, 1974), pp. 359-568.

26 For a discussion of the biblical, theological, and philosophical basis for the 'personhood from conception' position, see John Jefferson Davis, *Evangelical Ethics: Issues Facing the Church Today*, 2nd ed. (Phillipsburg, NJ: Presbyterian and Reformed, 1993), pp. 131-142.

both in humanity and the creation itself (Col. 1:19, 20). The healing ministry of Jesus was a demonstration of the truth and power of the kingdom of God proclaimed by Jesus (Matt. 9:35), and the alleviation of genetic diseases is consistent with God's redemptive purposes.

From the perspective of New Testament theology, the kingdom has 'already' arrived in power in the proclamation and actions of Jesus, but it is 'not yet' fully realized, awaiting the consummation of all things at the return of Christ. Consequently, Christian faith guards against *utopian* and unrealistic expectations of what genetic science can deliver in this life. Christian faith awaits the *new creation,* for only there will the results of sin—death, disease, pain, and deformity—be finally and completely overcome (Rev. 21:1-5; Rom. 8:21, 22), and all things made completely new.

Ethical reflection on the issues raised by genetic technologies can be informed by perspectives reflecting the three frameworks and five factors that would apply to the analysis of moral issues generally.[27] The problems raised by genetic interventions can be considered from the perspectives of *deontological, teleological,* and *consequentialist* ethical theories.[28] Deontological theories emphasize duties, rules, and normative principles, and seek to determine what is intrinsically right in a given situation, with 'usefulness' or consequences as secondary considerations. A deontological approach to genetic issues would call attention, for example; to such values as the sanctity of human life and the demands of justice for both the individual and the social order. The concept of the sanctity of life is highly relevant, for example, to discussions of embryonic stem-cell research and the treatment of human embryos.

Teleological or goal-oriented theories could be characterized as ethics of *vision,* asking such questions as 'What does a good human life look like?', or, 'What does a good society look like? What choices should we be making in order to get from 'here' to 'there'?' Discussions of *character* or *virtue ethics* would fit within this general approach. This ethical framework might suggest such questions, in relation, for example, to proposals for human enhancement by genetic engineering, as 'What type of human beings should we seek to become? Is it in fact desirable to try

27 For a discussion of methodology in Christian ethics, see John Jefferson Davis, *Evangelical Ethics: Issues Facing the Church Today*, 2nd ed. (Phillipsburg, NJ: Presbyterian and Reformed, 1995), pp. 1-13; on methodology in bioethics, see Tom L. Beauchamp and James Childress, *Principles of Biomedical Ethics*, 3rd ed. (New York: Oxford University Press, 1989).

28 From a biblical perspective, these perspectives could be seen as complementary rather than as mutually exclusive. Biblical warrant can be found for all three approaches. The Ten Commandments are a paradigm of a deontological, law-oriented ethic. The Sermon on the Mount provides a basis for a New Testament teleological ethic, inasmuch as it reveals Jesus' vision of what a true disciple and life in the kingdom should look like. The legitimacy of consequentialist considerations are presupposed in the teachings of Jesus on *counting the cost* of discipleship (Lk.14:25-35).

to create humans who are smarter, taller, or stronger? Do we really want to create a new society of genetic 'haves' and 'have-nots'?'

Consequentialist or *utilitarian* ethical systems focus on consequences or outcomes. Such a framework raises questions of 'the greatest good for the greatest number'. Sometimes called 'cost-benefit' ethics, such utilitarian approaches raise questions such as 'What utility or benefits are produced by a given choice or social policy? Are the benefits worth the costs that are involved?' In practice, in any utilitarian calculation the further questions need to be addressed, 'Benefits *for whom?* Costs *for whom?* ' Social costs and social benefits should be justly distributed; a utilitarian calculation ought not to be abstracted from deontological considerations of intrinsic fairness.

A utilitarian perspective, informed properly by deontological and teleological considerations can be fruitfully applies to issues of genetic intervention. For example, in relation to government funding of research in the area of genetic therapies, issues of costs vs. benefits inevitably arise. From the perspective of an individual afflicted with a rare genetic disorder such as SCID (severe combined immune deficiency), it is highly desirable that money be spent on seeking a cure. The policy maker, however, must ask such questions, 'Given our limited financial resources, how much should we spend in seeking a cure for SCID, and how much for cures for cancer or heart disease? How can we achieve the greatest good for the greatest number, and be fair and just in the process?'

Christian ethical analysis on genetic interventions can be informed also by the consideration of the following five factors or questions: norms, context, intention; means, and consequences. The first consideration, *norms,* has already been implied in the prior discussion of deontological ethics. Here the question would be, 'Is this genetic intervention consistent with the commands, precepts, and principles of scripture?' For example, those who believe that human life begins at conception, would find that the deliberate creation and destruction of human embryos for research purposes would violate the biblical principle of the *sanctity of life.*

The fifth factor, *consequences,* has also been discussed in relation to the utilitarian approach to ethics. Here the questions might be, 'What would be the consequences of these technologies—in the short and long term—for the individuals involved and for society?' It could also be noted that human beings have an imperfect ability to fully anticipate the consequences of a given action. For example, when *in vitro* fertilization techniques were first introduced to the general public, they were assumed to be safe for the children born as a result. Now, however, several studies have found evidence of small but significant increases in the incidence of birth defects for children conceived by this technique.[29] The long-

29 See Michele Hansen, et al., 'The Risk of Major Birth Defects after Intracytoplasmic Sperm Injection and In Vitro Fertilization,' *New England Journal of Medicine* 346: 10 (2002), pp. 725-30; and Laura A. Schieve, et al., 'Low and Very Low Birth Weight in Infants Conceived with Use of Assisted Reproductive Technology,' *New England Journal of Medicine* 346:10 (2002), pp. 731-37.

term consequences of a given action may be especially difficult to foresee. In light of the imperfections of human forecasting, it is all the more necessary to make ethical decisions within a deontological perspective that is based on principles and duties that are not limited merely to a special context or short-term benefits

Biblical ethics teaches that certain choices are right and good only within the proper *context,* e.g., sexual intercourse within the context of marriage. Questions of proper context can inform reflection on genetic issues that can impact the family and the parent-child bond. For example, it might be pointed out that techniques such as *pre-implantation genetic diagnosis*, at times now practised in connection with in vitro fertilization, is not a technique that should be abstracted from the context of family dynamics. Here the questions could be raised, 'How will this technique, which can select for a genetically "perfect" child, affect the parents' perception—or society's perception—of less-than-perfect children already born? Will it make parents and society less compassionate toward the handicapped?'

Biblical ethics teaches, with regard to the factor of *intention,* that for an action to be fully pleasing to God, that action must be done with right intent. Right intentions or motivations are those which are impelled by the love of God and neighbour (Mt. 22:37-40) and which seek to glorify and honour God (1 Cor. 10:31). Good intentions are necessary but not *sufficient* conditions for ethically right actions. Christian ethics recognizes the deceitfulness and self-justifying tendencies of the human heart; 'good intentions are good, but good intentions alone are not enough.'

Finally, right actions require not only conformity to biblical norms; the proper context; right intention; good consequences or results; but *right means* as well. Good consequences are not to be produced by morally illegitimate means. The apostle Paul asks, 'Shall we do evil that good may come? Their condemnation is deserved' (Rom. 3:8). Using human subjects to test dangerous genetic therapies apart from full and informed consent regarding the possible risks could not be justified merely by appealing to the possible cures to be discovered. Human beings are not to be used solely or only as means to someone else's benefit.

The theological and ethical considerations developed here from a biblical perspective are not uniformly shared in the wider culture, and this of course complicates Christian efforts to be 'salt and light' in the public policy debates on the issues raised by the new genetics. Evangelical Christians are no longer the dominant shapers of the public culture in America, and the postmodern sensibility of pluralism, relativism, and pragmatism seems suspicious of all[30] moral absolutes. The pluralism of ethical values in American

30 For statements of postmodernism, see, for example, Jean-Francois Lyotard, *The Postmodern Condition: a Report on Knowledge* (Minneapolis: University of Minnesota Press, 1984); Richard Rorty, *Philosophy and the Mirror of Nature* (Oxford: Basil Blackwell, 1980). For assessments of postmodernism from an evangelical perspective, see David S. Dockery, ed., *The Challenge of Postmodernism: an Evangelical Engagement* (Wheaton, IL: Victor Books, 1995), and Gene Edward Veith, Jr., *Postmodern Times* (Wheaton, IL: Crossway Books, 1994).

culture makes it difficult if not impossible to adjudicate rival perspectives on such contentious issues as abortion or the moral status of the human embryo. Nevertheless, an evangelical voice, even if it is not the dominant voice, needs to be heard in the public square. Evangelicals can be 'salt and light' in the culture by witnessing to the sanctity of human life from its inception and to the non-reducibility of human life to its chemical and genetic constituents. Evangelicals can be counter-voices to the utilitarian and secular ways of thinking that could be too easily driven by the powerful forces of big science, big government, and the biotech industry.

Reflections on the Issues:

Since the 1960s *genetic testing and screening* has become available for a constantly growing list of genetic disorders including Down syndrome, muscular dystrophy, cystic fibrosis, sickle cell anaemia, PKU disease, Huntington's disease, Tay-Sachs disease, haemophilia, Lou Gehrig's disease, and certain forms of breast cancer.[31] The screening of newborn infants for the rare metabolic disorder phenylketonuria (PKU), which can cause mental retardation but which can be treated with a special diet, came into use in the early 1960s. In the 1970s screening of African-American infants for sickle-cell anaemia and of Ashkenazic Jews for Tay-Sachs disease was introduced in various localities.

Prenatal genetic tests can be performed using techniques including amniocentesis, alpha fetoprotein testing (AFP), or chorionic villus sampling (CVS), which examine the amniotic fluid, foetal cells, or the maternal or foetal blood.[32] Amniocentesis, usually carried out at about the sixteenth week of pregnancy, is frequently offered to pregnant women 35 years of age or older who are thought to be at increased risk of giving birth to a child with Down syndrome or some other genetic disorder. There is a slight but significant (one-half of one percent) risk that the procedure of amniocentesis itself may cause a miscarriage. The miscarriage rate associated with chorionic villus sampling is believed to be on the order of one to two percent.[33]

Pre-implantation genetic diagnosis (PGD), which involves the removal of one or more cells from the embryo developing in vitro, was first described in 1989 and has been used to diagnose cystic fibrosis, Tay-Sachs disease, sickle-cell anaemia, PKU, and other disorders.[34] There appear to be no adverse short-term effects, but long-term data is unavailable. This proce-

31 A standard reference work in this area is R.J. Gardner and Grant R. Sutherland, *Chromosome Abnormalities and Genetic Counseling* (New York: Oxford University Press, 1996). General background information is provided in the article 'Genetic Testing and Genetic Screening,' National Reference Center for Bioethics Literature, Georgetown University, <www.georgetown.edu/research/nrcbl/scopenotes/sn22.html>

32 These procedures are described in Gardner and Sutherland, cited above, pp.336-44.

33 Elizabeth Kristol, 'Picture Perfect: the Politics of Prenatal Testing', *Ethics and Medicine* 9:2 (1993), pp. 23-31 at 24.

34 Thomas H. Murray and Erik Parens, 'Preimplantation Genetic Diagnosis: Beginning a Long Conversation', *Medical Ethics* 9:2 (Spring 2002), pp, 1,2,8.

dure, which currently is costly and technically demanding, could become more common in the future.

By the late 1990s over 500 laboratories in universities, health departments, and commercial agencies were offering genetic testing.[35] It has been suggested that parents or prospective parents could be advised to consider genetic testing when one or more of the following five conditions obtain: 1) one parent has a genetic disorder; 2) the parents already have a child with a genetic disorder; 3) there is a family history of genetic disease; 4) the individual is known to be a carrier (e.g., the daughter of a father with haemophilia); or 5) the individual is a member of an ethnic group known to be at greater risk for a genetic disorder (e.g., Ashkenazic Jews for Tay-Sachs, or African-Americans for sickle-cell anaemia.[36]

Those who are considering genetic testing will need to consider issues of cost; the reliability of the test and any risks involved; issues of privacy and disclosure to other family members; the availability of treatment for any disorder that may discovered and the impact of such information on the emotional and psychological well-being of the individual and other family members.[37] Those who are committed to the biblical teaching of the sanctity of life and who believe that human life begins at conception would not use such information for the selective abortion of genetically handicapped children. Genetic counsellors, who can provide medical background information and help in the interpretation of test results and probable risks are available through referral from the National Society of Genetic Counselors.[38]

In 1990 researchers at the U.S. National Institutes of Health performed the first officially-sanctioned *gene therapy,* treating four-year old Ashanti DeSilva for a rare genetic disease, severe combined immune deficiency (SCID), which left her body vulnerable to every passing germ.[39] In this procedure the researchers removed white blood cells from the child's body, grew the cells in the laboratory, spliced missing genes into the cells, and rein-

35 James C. Peterson, *Genetic Turning Points: the Ethics of Human Genetic Intervention* (Grand Rapids, MI: William B. Eerdmans, 2001), p. 150.

36 John C. Fletcher, *Coping with Genetic Disorders: a Guide for Clergy and Parents* (New York: Harper & Row, 1982), pp. 26, 27. Fletcher provides helpful insights and case studies for pastoral counseling in this area.

37 Helpful discussion of such issues from a 'consumer's' perspective may be found in Doris Teichler Zallen, *Does It Run in the Family? A Consumer's Guide to DNA Testing for Genetic Disorders* (New Brunswick, NJ: Rutgers University Press, 1997). The social and legal questions concerning privacy, confidentiality, and possible discrimination in heath insurance and employment are addressed in Lori B. Andrews, *Future Perfect: Confronting Decisions about Genetics* (New York: Columbia University Press, 2001), and also in Justine Burley and John Harris, eds., *A Companion to Genethics* (Oxford: Blackwell Publishers, 2002), Part V, 'Ethics, Law, and Policy,' pp. 349-407.

38 The current website for this organization is www.nsgc.org .

39 'Human Gene Therapy,' National Reference Center for Bioethics Literature, Georgetown University, <www.georgetown.edu/research/ncrbl/scopenotes/sn24.html> A comprehensive treatment of the issues raised by gene therapy can be found in Leroy Walters and Julie Gage Palmer, *The Ethics of Human Gene Therapy* (New York: Oxford University Press, 1997).

troduced the modified cells back into her bloodstream. While not providing a permanent cure, Ashanti's immune system was improved and she was subsequently able to attend school.

By the end of 1993 gene therapy protocols had been approved for cystic fibrosis, Gaucher's disease, and a number of other conditions. The death in October of 1999 of Jesse Gelsinger, the first known fatality in a gene therapy experiment, led to public demands for greater accountability and governmental oversight for such work.[40] The completion of the draft sequencing of the human genome in June of 2000, making available to scientists a greatly expanded knowledge base for studying genetic disorders, is very likely to increase dramatically the interest in and demand for new human gene therapies.

Earlier ethical discussion of gene therapy tended to be favourable, in principle, to *somatic cell* therapies that altered various body cells, but resistant toward *germ-line* therapies that would alter the human ovum or sperm, and so affect future generations.[41] If, however, in a given case it could be firmly established, on the basis of rigorous clinical trials, that such therapies were safe and effective, it would seem that germ-line interventions would not be inconsistent with a general Christian mandate to alleviate human suffering. As James Peterson has observed, such healing work can reflect God's gracious redemption. If the elimination of smallpox from the globe was a real benefit, then we might surely agree with Peterson that wiping out '… Tay-Sachs, Huntington, or Alzheimer's disease from our genetic heritage would be as well'.[42]

The subject of *genetic enhancement* is highly controversial. If it should become possible at some time in the future to safely and effectively alter through genetic interventions human characteristics such as height, intelligence, need for sleep, memory, or lifespan, should such interventions be permitted or encouraged? The possibility of such interventions may be unlikely in the near future, given the complex, multifactorial, and at present poorly understood nature of the causal connection between these traits and the human genome. Nevertheless, given the rapid advances in genetic knowledge, such questions are not entirely hypothetical, and bear critical scrutiny.

Those who have favoured various genetic enhancements have argued that parents already seek to enhance their children's life prospects through education and other means, and that these technologies would be only an extension of current practices and attitudes; that the 'right to procreate' encompasses a right to make such choices for one's children; that the state should not limit individual choice, since such choices do no harm but rather produce benefits for the

40 'Human Gene Therapy,' p. 2, cited in note 39 above.

41 For the history of this discussion and a summary of the arguments for and against germ-line therapies, see Walters and Palmer, *The Ethics of Human Gene Therapy*, pp.60-98.

42 Peterson, *Genetic Turning Points*, p. 321. See pp. 306-321 for Peterson's discussion of the debate on germ-line therapies.

recipients; that the ends of such technologies—intelligence, longer lifespan, improved memory, etc.—are inherently desirable; and that in any case, it would be difficult if not impossible to prohibit the use of such technologies once they became generally available.[43]

Critics of genetic enhancement have argued that such intervention would represent 'playing God,' a tampering with the human nature ordained by God; that there is no social consensus on what constitutes 'ideal' humanity; that it could exacerbate existing prejudices against handicapped persons; that it could lessen the diversity of the human gene pool; that it could foster further class divisions and undermine the premise of equality upon which democracy is based.[44]

The arguments for and against genetic enhancements, involving as they do conflicting notions about such fundamental questions as the nature of human nature, individual rights, parenthood, and the limits of state power, are not easily resolved. These issues call for serious reflection and debate during the years ahead as technology continues to advance.

The subject of *human cloning* has received heightened attention in the wake of the cloning of the sheep 'Dolly' by Ian Wilmut and his colleagues in Scotland in 1997. Dolly was created from one embryo that survived out of a total of 277 at the start of the experiment, raising grave questions about the safety of such procedures. In a subsequent interview Wilmut himself expressed strong opposition to human cloning, saying that such attempts would be 'appallingly irresponsible', since any children born as a result would likely '… die within a few day of birth'.[45] Studies performed by researchers at Japan's National Institute of Infectious Diseases found that cloned mice died significantly earlier than their naturally-born counterparts, giving clear evidence that the cloning process caused life-shortening biological abnormalities.[46]

Public opinion polls have registered strong opposition to human cloning. A poll by ABC's *Nightline* program released the day after the Dolly announcement reported that 87 percent of those polled supported a ban on

43 The arguments on this issue of genetic enhancement are reviewed in Walters and Palmer, *Ethics of Human Gene Therapy*, pp. 99-142. A cautiously favourable stance is presented in James Peterson, *Genetic Turning Points*, pp.275-288, and also in John Jefferson Davis, 'Human Enhancement Genetic Engineering and the Image of God,' cited in note 1 above.

44 This last point is a major premise in Francis Fukuyama, *Our Posthuman Future: Consequences of the Biotechnology Revolution*, p. 7: '... a technology powerful enough to reshape what we are will have possibly malign consequences for liberal democracy and the nature of politics itself.'

45 Ian Wilmut, 'The Ethics of Cloning,' *The American Enterprise* 9:5 (1998), p. 57; and Rudolf Jaenisch and Ian Wilmut, 'Don't Clone Humans', *Science* 291:5513 (2001), p. 2552; for further scientific background on the techniques of cloning, see Jose B. Cibelli, Robert P. Lanza and Michael D. West, 'The First Human Clone,' *Scientific American*, January 2002, pp. 44-51, and the website <www.sciam.com/explorations/2001/112401ezzell/>

46 Raja Mishra, 'Shorter Lifespan Found in Study of Cloned Mice', *Boston Globe* (February 11, 2002), p. A1.

human cloning.[47]

Even apart from considerations of safety, there are a variety of weighty objections to human cloning. Such techniques endanger human dignity by treating human persons as commodities to be manufactured, rather than as treasured members of a family covenant.[48] Healthy family relationships could be undermined, inasmuch as reproductive cloning would erode the child's sense of separateness from the parents and siblings that is necessary for healthy psychological development.[49] From the perspective of a Christian theology of the Trinity, which sees the divine community of three *distinct* persons—Father, Son, Holy Spirit—as a paradigm for human relationships, human cloning would intentionally undermine the sense of *individuality* that is an integral value for human persons, and so be unacceptable.

So-called 'therapeutic cloning,' which involves the deliberate creation of human embryos for the purpose of harvesting their stem cells for research purposes, is likewise ethically unacceptable. The stated *ends* of such manipulations—to use the stem cells to treat conditions such as Alzheimer's disease or muscular dystrophy—do not justify the *means* that are involved: the deliberate destruction of the embryo for someone else's benefit.[50]

Concluding Reflections

This discussion will conclude by recalling the prediction made by Francis Fukuyama in his recent book, *Our Posthuman Future: Consequences of the Biotechnology Revolution.* According to this influential political scientist and social philosopher, genetic engineering will eventually prove to be '… the most consequential of all future developments in biotechnology,' because 'human nature is fundamental to our notions of justice, morality, and the good life, and all these will undergo change if this technology becomes widespread'.[51]

47 Cited in Ben Mitchell, 'A Protestant Perspective on Cloning', *Ethics and Medicine* 14:1 (1998), pp. 26-30, at 26. As early as 1994 the Embryo Research Panel of the National Institutes of Health had recommended against the federal funding of human reproductive cloning: 'Major Conclusions and Recommendations from the Final Report of the NIH Human Embryo Research Panel', *Ethics and Medicine* 11:1 (1995), pp. 20-23.

48 Mitchell, 'A Protestant Perspective on Cloning', p. 29. See also John S. Grabowski, 'Made Not Begotten: a Theological Analysis of Human Cloning', *Ethics and Medicine* 14:3 (1998), pp. 69-72.

49 Helen Watt, 'Thinking Twice: Cloning and In Vitro Fertilization,' *Ethics and Medicine* 18:2 (2002), pp. 35-43 at 37. Similar concerns are raised by Kurt A. Richardson, 'Human Reproduction by Cloning in Theological Perspective', *Valparaiso University Law Review* 32:2 (1998), pp. 739-752. A range of religious opinions on human cloning is found in Ronald Cole-Turner, *Human Cloning: Religious Responses* (Louisville: Westminster/John Knox Press, 1997).

50 For background on the scientific issues surrounding embryonic stem cell research, and concerns about the safety of introducing such cells into the bodies of human subjects, see Maureen L. Condic, 'The Basics About Stem Cells,' *First Things*, January 2002, pp. 30-34.

51 Fukuyama, *Our Posthuman Future*, pp. 82, 83.

Genetic engineering is fraught with potentially enormous consequences, since it promises to give humanity the power to alter the nature of human nature itself. Those who understand the nature and purpose of human life from a biblical perspective need to be heard in present and future debates about the direction these new technologies should take. Otherwise, the biotechnology revolution is likely to be driven primarily if not exclusively by scientific and business elites with little accountability to the general public. This brief discussion has attempted to provide Evangelical Christians with some of the necessary concepts and perspectives that can help them to contribute to these conversations in significant ways.