Judeo-Christian thought regarding human gene manipulation and the Human Genome Project.

C. Scott. Robinson

University of Windsor
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Judeo-Christian Thought Regarding Human Gene Manipulation
and the Human Genome Project

by

C. Scott Robinson

A Thesis
Submitted To the Faculty of Graduate Studies and Research
through the Department of Religious Studies
in Partial Fulfillment of the Requirements for
the Degree of Master of Arts at the
University of Windsor

Windsor, Ontario, Canada

1996

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ABSTRACT

How does theological thought help to elucidate our understanding of the issues of human gene manipulation that arise from the Human Genome Project? To answer this question the thesis presents a brief history of the science that lies behind the Human Genome Project and surveys various religious groups and theologians from the Judeo-Christian traditions. From the views of these theologians and traditions various themes arise. The themes are translated into principles which are developed and presented as a means of interpreting specific issues that arise from human genome research. The principles used to interpret the issues that arise are the sanctity of life, imago Dei, co-creation/co-responsibility and justice. Through an interpretation of selected issues with these principles it is concluded that theological thought helps to elucidate an understanding of human gene manipulation.
DEDICATION

For my mother and father
who gave me the very essence of who I am.
For my brother who is like me.
For our children
who depict
the very essence of what will
become of us all.
ACKNOWLEDGEMENTS

My thanks are extended to my advisor, Dr. Maureen Muldoon and the other members of my committee, Dr. G.H. Crowell and Dr. M.L. Petras. I thank Dr. Dorothy Sly for valuable feedback in the early stages of my writing, Vicki Kett for answering all of my questions, and Dr. Philip Boyle at the Hastings Center.
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Introduction

During the past two decades geneticists from around the world have been working on the Human Genome Project, a multibillion dollar project of mapping and sequencing the entire human genome.¹ The Human Genome Project is likely to have many ramifications including an increased ability to perform genetic manipulations, or alter the genetic make-up of human beings. In addition, the Project research now taking place is expected to have vast implications for future discoveries in science and medicine.

This is an important subject to investigate because it focuses on an intersection point of two disciplines which have a deep historic relationship: science and theology. Arising from this relationship, we are faced today with trying to discover the ramifications for being human in light of projects such as genome mapping.² These ramifications are especially important in societies that are highly technological and assert a pluralistic vision of themselves, since it is within these societies that the technology is being developed and the research is being conducted.³

Theology has begun to deliberate on the ethical issues of the Genome Project and gene manipulation.⁴ The


²See Daniel Callahan's discussion on the sanctity of life in Updating Life and Death.

³AbbyAnn Lynch questioned whether we would use the results of gene therapy and identifying the human genome to identify our differences or to acknowledge our common humanity.

⁴The ethical issues I interpret are genetic screening, enhancement manipulations, eugenics, genetic discrimination, just distribution and resource allocation, privacy and confidentiality, as well as patenting and piracy of human genetic material.
theological perspectives of Rabbi Immanuel Jacobovitz, Joseph Fletcher, Paul Ramsey, Charles Curran, James Gustafson, and others, are paramount in this discussion.\(^5\) In addition the most recent statements of the Catholic, Anglican Church of Canada, United Church of Canada, and selected Jewish traditions are important.\(^6\) Current statements from the World Council of Churches (WCC) can also be drawn from.\(^7\)

The influence of faith communities on these issues will continue to have an impact on policy making as theological thinkers will offer their considerations and ideas to those in their faith communities and to society in general.\(^8\) Through personal reflection the lay person will be enabled to embrace traditional faith commitments in regard to the issues surrounding the Genome Project. Genetic manipulation is likely to result in several implications for medicine and health care that may have an impact on the lives of all human beings. Through personal reflection on the theological voices, and by taking into account church statements, the lay person will be better able to make

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\(^5\) Although some of the authors, such as Joseph Fletcher, have books dated after 1980, their ideas date back to the previous two decades.

\(^6\) This information will be taken from conference papers, respona and other working papers that come directly from the particular traditions. The responses of the Churches are provided to survey the interest of major religious bodies on a topic of such magnitude as genetic manipulation.

\(^7\) The World Council of Churches is a federation of member churches consisting of most Protestant and Orthodox churches around the world. With its base in Geneva, Switzerland, the WCC deals largely with maintaining ecumenical unity. The initial mandate of the World Council was to relate Christian faith to social issues. The WCC attempts to continue this task through regular assemblies around the world. It is because of this mandate to relate the Christian faith to social problems that the WCC is important to this research.

practical decisions regarding these issues.\textsuperscript{9}

Judeo-Christian thought helps to elucidate an understanding of the issues of human gene manipulation which arise from the Human Genome Project by offering certain themes and symbols that arise from the traditions and may give guidance to ethical decision-making regarding gene manipulations.\textsuperscript{10} An examination of the biological basis of the Human Genome Project and gene manipulation followed by a survey of theological discourse surrounding genetic engineering, gene manipulation and the Human Genome Project, from the early 1960s to the present, indicates four theological convictions and principles drawn from various Judeo-Christian traditions that may be used to interpret issues regarding gene manipulations. These hermeneutical principles\textsuperscript{11} and convictions are the doctrine of \textit{imago Dei}, the sanctity of human life, co-creation/co-responsibility and justice.

I align my own personal beliefs with themes that arise from the theologians and traditions to be discussed. The personal convictions that aid in my understanding of the issues are: 1. if it were not for God I would not be living and because I am alive my life is sacred; 2. I live my life to do the works that God has planned for me to do; 3. in doing these works I am responsible for other human beings; 4. from these works love is created.

Based on the hermeneutical principles drawn from the

\textsuperscript{9}It is important to note that because this is a relatively new area there appears to be little information on the views of the lay person.

\textsuperscript{10}Drawing from various Judeo-Christian traditions, the author will look for corresponding and unique points of view to gain an understanding of how these traditions influence decision making in this area.

\textsuperscript{11}The term hermeneutical principles is used to indicate the theological guidelines that are used by the theologians who are involved in the ethical discourse on gene manipulations and the Genome Project.
traditions and theological thinkers, as well as my own personal convictions, I argue that human gene manipulation and the Genome Project can be warranted both scientifically and ethically. Nonetheless, the Genome Project and gene manipulation remain questionable because of the many possibilities for misuse, the immensity of the Genome Project giving a high probability of unforeseeable consequences, and because the Project and gene manipulation appear to service the needs of the affluent and ignore those marginalized in our society.
Chapter One: A Biological Basis

Many authors imply that genetics has had a relatively short existence, being approximately one century old. Some sources insinuate that Darwin's theory of Evolution was the beginning of genetics.¹² This is not entirely accurate. Humans have been aware of genetics, that is the inheritance of characteristics, for far longer than the last century. The Bible cites many accounts that acknowledge the application of genetic knowledge. For example, in Chapters thirty and thirty one of the book of *Genesis* there is the account of Jacob's and Laban's sheep. Jacob bred a superior flock of sheep, implying a genetically stronger flock.

Other examples of human awareness of genetics date to the days of the hunters and gatherers. Two examples are saving seeds that produced superior plants (high yielding plants or ones that would grow well in a particular climate) and families avoiding inbreeding. The point is that humans may very well have had genetic knowledge long before we have record of it.

It is important to take a look at how genetics has progressed from its unassuming beginnings so that an understanding of why Judeo-Christian thought is concerned with the present state of genetic knowledge and research. This brief history sets the foundation for the vast undertaking of the Human Genome Project that involves mapping and sequencing the human genome.

Francis Galton and his contemporary, Gregor Mendel, an Augustinian monk, were two of the first scientists that could be labeled geneticists, although the term "gene" was not coined until later. Both men were interested in inherited traits. Galton was interested in quantitative

characteristics and the inheritance of "genius." One of his initial research experiments was to transfuse blood from black rabbits to white ones to determine whether their color was passed through the blood.\textsuperscript{13} In 1911 Galton donated money to begin the Laboratory for National Eugenics at University College in London. Mendel focused his study on peas. It was Gregor Mendel who had the initial idea of what is now known as the "gene." This notion was that both pollen and eggs carried particles that contained instructions for determining the structure of peas and other organisms. Mendel was shunned by leading biologists of the day and his work ignored, as other scientists were more interested in how an unstructured egg develops into a more complex form such as a human being. Essentially they asked what we still ask today: "What does it mean to be human?"\textsuperscript{14}

Later, at Columbia University in New York, T.H. Morgan began studying the fruit fly, \textit{Drosophila melanogaster}. Differences in genetic traits became apparent immediately because of the ease in breeding fruit flies. As a result of a mutation that occurred in the breeding of fruit flies, Morgan began to concern himself with the question of where the genes were located. It was concluded that genes were located on chromosomes and linked to one another, although these linked genes would tend to split as time passed. This led to the development of linkage maps. These maps provided a clear picture of how the genes were arranged on the chromosome so their information could be translated into ordered instructions.

During the "roaring twenties" scientists discovered

\textsuperscript{13} Jones & Van Loon, \textit{Genetics For Beginners}, 12.

that x-rays would cause genetic mutations. Nucleic acids were known long before genetic mutations were recognized but further study on mutations resulted in the identification of the nucleic acids deoxyribonucleic acid (DNA) and ribonucleic acid (RNA). DNA was later implicated as the genetic molecule.

Francis Galton first aroused interest in eugenics in the 1800’s. Early in the following century Eugenics Movements began to gain popularity. These movements had the goal of improving the human race by breeding out unwanted characteristics through the sterilization of those people deemed by greater society to be physically or mentally unfit to reproduce. Immigration to the United States was limited by the U.S. Immigration Act that was based on racial and ethnic grounds and pushed by the eugenics movements of the day. Several American states, including California, Washington, New York, Michigan and Indiana implemented compulsory sterilization laws that were justified by the government of the United States.

One Canadian example of the eugenics movement was the Ontario based Eugenics Society of Canada whose membership consisted of "university professors, lawyers, public health officers and politicians." Other eugenics groups had members such as prominent geneticists and lay people. Canada's most western provinces, Alberta and British

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15 Steve Jones refers to this in his book *Genetics for Beginners*. A better reference to this work occurred in the 1940’s and was completed by George W. Beadle and Edward L. Tatum. Reference to this work can be found in William K. Purves et al, *Life: the Science of Biology*, 236.


17 ibid, 101.

18 ibid, 100.
Columbia, lay claim to early sterilization policies for the "feebleminded." These policies preceded Nazi power in Germany. Further Eugenics Movement action took place in the 1930's and climaxed with Nazi Germany in the 1940's. The Nazi Germans sterilized so-called "defective" people and exterminated millions of Jews with the same intent as the North American eugenics movement.

Historian Angus McLaren writes that these eugenics policies were prompted by societal anxiety. During the Great Depression many people in Canada and the U.S. were searching for answers to society's ills.

When people were looking around to find out the causes of the nation's discomfort, it was far easier to think of these problems originating from the individual flaws of the feeble-minded, of the physically incapacitated, of the diseased, and suggest that if only these individuals were somehow removed or if they were prevented from reproducing, then healthy people, the normal people, could get on with their lives. 19

After the Second World War and because DNA and RNA had been identified progress in genetics was catapulted forward. James Watson and Francis Crick worked together to develop the idea of DNA being a double helix through working with X-ray diffraction and other techniques. In 1953 they announced that the pairing of nucleotides in the form of a double helix could potentially result in a copying mechanism for genetic material. 20 The processes for copying genetic material are known as translation and transcription. 21

Three years later, in 1956, twenty-three pairs of

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21 Good descriptions of translation and transcription can be found in David Suzuki and Peter Knudson, Genetics (Toronto: Stoddard, 1988) and Robert H. Tamarin, Principles of Genetics (Dubuque, Iowa: Wm. C. Brown Publishers).
chromosomes were identified in human body cells. Before this discovery, it was believed that the human body had forty-eight pairs of chromosomes. A decade after this discovery the complete genetic code of DNA was unraveled.

One of the prominent genetic breakthroughs of the 70's was the development of sequencing techniques that enabled scientists to list the properly ordered DNA texts of a gene formed with the nucleotides adenine (A), thymine (T), cytosine (C) and guanine (G). The 1970's also brought a great deal of research on recombinant DNA (DNA formed from various sources). Early recombinant DNA molecules were created through a process of combining genes from various organisms such as combining genes from human hormones with *Escherichia coli* DNA. The result of this experiment was a bacterium that could synthesize a human hormone.

Research and development in the area of genetics and biotechnology have increased dramatically since the early 80's. The 80's brought diagnosis of certain diseases by means of prenatal DNA analysis. Insulin was created by recombinant DNA techniques and injection of humans with engineered genes was attempted to replace genes that were deemed defective. Although the first gene therapy experiments were done, they were unsuccessful and had not passed the approval of an ethics committee. The most

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23 Recombinant DNA is DNA that is formed from combining DNA from two different species, for example, mice and human DNA.


prominent undertaking that began in the 1980's is the Human Genome Project, which aims to map and sequence the human genome.

The Human Genome Project

Although the history of molecular genetics is short, a great deal has been discovered. Geneticists are presently working on the Human Genome Project. It is perhaps the most significant project in science since the moon landing. It is important to understand the science that lies behind this work. Not only the science of mapping and sequencing but a general understanding of genetics will be essential. To understand the ethical issues it is necessary to discuss the Genome Project, mapping, sequencing, medical implications and selected types of gene manipulation.

The genome project is essentially two projects. One aim is to map and sequence the human genome, the other to develop an understanding of model organisms. Several countries are taking part in the activities of the project: the U.S., Canada, France, Italy, the United Kingdom, the members of the European Economic Community (EEC) and Russia. It is expected that the project will take approximately fifteen years to complete. The cost of this "Big Science" project totals $200 million per year in the United States alone. In the U.S. the funding is divided between the National Institutes of Health (NIH) and the Department of Energy (DOE). Several institutions and organizations around the world are involved in varying degrees in administering the genome project at different levels. The Human Genome Organization (HUGO) is a governing body that expects funding

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26 See the sections on mapping and sequencing.

from all nations involved with genome research. In Canada funding for research on the Human Genome Project comes from the Canadian Genome Analysis And Technology Program (CTAG). CTAG is funded by Industry Canada, the Medical Research Council of Canada, the Natural Sciences and Engineering Research Council of Canada and the Social Sciences and Humanities Council of Canada.

The first phase of the project involves mapping the genes that are located on the chromosomes. When this is completed the genes will be sequenced.\(^{28}\) It is important to distinguish between mapping and sequencing because they are very different processes. Maps show the placement of genes and sequences indicate the nucleotide arrangement within the DNA. The two are often compared to geographical maps. Sequences are the territory and the maps are "features of the terrain identified."\(^{29}\) In the mean time, to enable scientists to determine the function of the sequences with greater ease, model organisms will be mapped and sequenced. This project is important because the genes in these organisms function similarly to those in humans. There are four organisms to be modeled: Eschericia coli (E.coli), Caenorhabditis elegans (worm), Drosophila melanogaster (fruit fly), and Mus musculus (mouse).

Because sequencing the entire human genome involves the collection of massive amounts of information, new data collecting and analyzing techniques have been and are in the process of being developed. It has been indicated that the total sequence of the human genome will be equal to a

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\(^{28}\) For an in-depth look at how mapping and sequencing are done see Tamarin, *Principles of Genetics*. These topics are also discussed later in this chapter.

\(^{29}\) Kelvers and Hood (editors), *The Code of Codes*, 79.
thousand thousand page telephone books. More advanced computer programming will be essential to accommodate the magnitude of this information. There is some question as to the usefulness of such information as well as a question of the validity of sequencing the human genome. It is likely, however, that the maps and sequences will provide the medical community with an invaluable tool for developing treatments for various diseases. Although there is no problem with mapping the entire genome, some suggest sequencing only particular genes because of the possibility that only some sequences will have a practical value.

Mapping

Gene mapping deals with locating the position of each gene on the chromosomes or finding the *locus*. There are different kinds of genetic maps: linkage maps and physical maps. Linkage maps are determined by the association of genes and markers on the chromosomes. Physical maps consist of the position of a gene on a chromosome.

Mapping the twenty-four linkage groups of the human being is done in various ways. Mapping human chromosomes is made difficult by small family sizes, the inability to make specific crosses and the unethical nature of conducting human experiments. To combat these difficulties the first extensive mapping used the X chromosome. Because males have only one X chromosome, locus patterns on the X chromosome are easily traced and the relationship between

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31Tamarin, *Principles of Genetics*, 331-332[Box 12.2].

32The X chromosome determines what sex the offspring will be. Females have two X chromosomes and males have one.
such loci can be readily established. The autosomes (nonsex chromosomes) are more difficult to map. Two techniques have been developed that aid in mapping autosomes: chromosome banding and somatic cell hybridization. Chromosome banding involves the use of chemical stains that create patterns of cross bands on the chromosomes. This enables each chromosome to be identified in a karyotype (the chromosome complement of a cell). In addition, the chromosomal bands act as markers and allow geneticists to physically localize genes on the chromosomes.

Somatic cell hybridization, also referred to as Chromosome-mediated transfer, is somewhat more complex. The somatic cells of humans beings and mice are combined to form hybrid cells in cell cultures. The hybrid cells consist of some human chromosomes and all the original chromosomes of the mice. As the cells multiply, human chromosomes are lost, leaving only a small number and in some instances only one (not always the same one). If the product produced by a particular gene is known and if that product is present in a cell which has a particular chromosome, the gene for that product must be present on that chromosome. In addition, because an arm of a chromosome can be broken off, even more detail about the location of the gene can be obtained.

Further mapping techniques have been developed through the use of restriction fragment length technology. This technique implements the use of restriction enzymes to cleave DNA molecules into fragments. Each restriction

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enzyme has a target sequence of nucleotides. Therefore a DNA molecule should always be "cut" at the same point unless a mutation occurs. The fragment seen on electrophoresis should be the same in all normal individuals. A person with Cystic Fibrosis should give a different pattern. A probe can then be made of the unique fragment and be used in DNA hybridization experiments.

**Sequencing of DNA**

Sequencing involves finding the order of nucleotides in the double-helix structure of the DNA molecule. A DNA sequence would look like a long, unordered string of A, T, G, C. Sequencing can be done by the same means as locating genes with the use of restriction enzymes. A single strand of DNA is divided into short segments. DNA polymerase, a primer and four restriction enzymes (one that is radioactive) are added to the individual DNA segments. The synthesis can be stopped by adding one of four modified restriction enzymes. This results in DNA strands of various length. The sequence of each strand can then be identified by using electrophoresis and X-ray techniques. A simpler version of this technique uses florescent molecules, rather than radioactive ones, and the sequence can be identified by the human eye under a U.V. light.

Other techniques allow for rapid sequencing of DNA. The Chemical Method uses chemicals to deconstruct the DNA in different bases. Another method, referred to as the "plus-minus" method, was more recently developed and referred to as the Dideoxy Method. This method uses modified nucleotides which are inserted into the DNA sequence being

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36 A=Adenine, T=Thymine, G=Guanine, C=Cytosine.

synthesized and cause a break in the synthesis. Each strand of DNA is placed in a reaction mixture that produces strands of various lengths that are identified by electrophoresis. Separate reactions are performed for each of the four nucleotides. They are arranged according to size and are only a part of the complete DNA sequence. Electrophoresis is used to make a direct reading of the sequence of DNA that appears in a ladder like form. This type of rapid DNA sequencing allows scientists to decipher the base sequence before the role of the gene is known.\textsuperscript{38}

The techniques used in sequencing are becoming more efficient as technology progresses. With this technological progress sequencing and mapping will be accomplished with greater ease. Genes will be located with the use of rapid sequencing methods.

**Implications for Medicine**

It is anticipated that the Human Genome Project will create vast opportunities for advances in medicine. As research in the area of gene therapy increases "the implications for the practice of medicine using these strategies is staggering."\textsuperscript{39} The mapping and sequencing of the human genome will make it possible to locate genes that cause abnormalities and eventually lead to therapeutic healing for those abnormalities. Mapping and sequencing will open new doors in the field of diagnosis and therapy.\textsuperscript{40} As the human genome is progressively mapped and sequenced, there will be parallel advances in diagnostic tests to


\textsuperscript{40}Kelves and Hood, *The Code of Codes*, 155.
determine susceptibility to common diseases. This is where the Human Genome Project is connected to gene therapy.
Several experimental genetic therapies have already been tested on humans such as those for Adenosine Deaminase Deficiency (ADA), Ovarian cancer and Malignant melanoma. One source explains that the number of human gene therapy protocols "is already lengthening every year, and continuing advances in the Human Genome Project will quite surely stimulate the use of molecular therapeutics for an ever expanding range of human diseases."

Gene Manipulation

Gene manipulation, otherwise known as gene therapy, is a medical procedure to correct defective genes that can cause debilitating disease or the removal or repair of defective genes in living cells. In 1980 the first unapproved attempt at gene therapy for β-thalassemia (a blood disorder) was unsuccessful. This initial attempt involved gene transfer that had been developed in early research on animals. There are only a few gene therapies that have been tested through approved protocols such as those for ADA deficiency, AIDS and various forms of cancer.

The Human Genome Project will aid in developing gene therapies through its charting of gene maps. There is hope

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(and fear) that gene manipulation will be used as common medical procedures in the future, to eliminate debilitating diseases such as Alzheimer's and Cystic Fibrosis.

There are four different types of gene manipulation. The parameters of this thesis allow only a brief look at all four types of therapy. Attention will be focused on the form of therapy involving the germ-line. Somatic cell manipulation involves correcting disease-causing genetic material in human somatic cells with healthy genetic material. Germ-line manipulation involves inserting replacement genes into the patients' sperm or ova. This prevents their offspring from inheriting their genetic disorders. Enhancement genetic engineering has the potential to change eye color, height, weight, baldness and many other human characteristics that we may not want our offspring to inherit. Eugenic genetic engineering involves altering complex genetic combinations that result in human characteristics such as personality and intelligence.46

For the purposes of this thesis, only somatic cell and germ-line manipulations will be investigated. There is concern about enhancement manipulation and the type of eugenic engineering envisioned by the Nazis. The latter types of gene manipulation are likely to result as a furthering of germ-line manipulation and are discussed in the context of germ-line manipulation. In addition enhancement manipulations are discussed as ethical issues in the next chapter. Somatic cell therapy will be looked at briefly to present an understanding of what takes place with gene therapy, as this type of therapy has been completed.47


47The Council for Responsible Genetics (CRG) in the United States uses the term gene modification or manipulation rather than therapy because therapy indicates a health benefit.
Somatic Cell Gene Manipulation

In 1990, North American laboratories were ready for the initial application of somatic cell gene therapy.\(^4^9\) The first of the approved protocols took place in September of 1990: "A four year old girl suffering from ADA deficiency (adenosine deaminase is an important enzyme) received an intravenous infusion of her own gene-corrected T Lymphocytes."\(^4^9\) The girl's T cells were put in culture that promoted their growth and when they began to divide were replaced through intravenous injection. She continued to receive infusions on a regular basis. Data from this protocol and others showed that the therapy proved to be useful clinically. A later protocol for ADA gene therapy, in Italy, used information from the 1990 and 1991 protocols to improve the efficiency of the therapy.\(^5^0\) By 1992 there were eleven active gene therapy projects around the world with several others pending. In 1993 the registry for gene therapy listed twenty gene therapy projects.\(^5^1\)

\(^4^9\) Canada, Medical Research Council of Canada, *Guidelines For Research On Somatic Cell Gene Therapy In Humans*, (Minister of Supply and Services, 1990). It is also important to note that Martin Cline performed two gene therapy operations in 1980, one in Israel and the other in Italy, although they were not approved by an ethics committee.

\(^5^0\) Anderson, "Human Gene Therapy," 810.

\(^5^1\) Anderson, "Human Gene Therapy," 811. The author notes that the results from this study were not available at the time this article was written.

The several completed gene therapy projects show that somatic cell therapy works. There have been no side effects from the therapies and there is a "consensus that somatic cell gene therapy for the purpose of treating a serious disease is an ethical therapeutic option." \(^{52}\)

**Germ-Line Gene Manipulation**

Germ-line gene therapy is not practiced on humans. It is surrounded by many troubling questions. In 1991 the NIH in the United States began talks on the ethical implications of this type of therapy. \(^{53}\) Around the same time, the Medical Research Council of Canada expressed the view that there is no need to alter the germ-line of humans or use gene therapies to alter the genome of anyone who does not suffer from a debilitating disease. \(^{54}\) Many of the ethical questions raised about gene manipulation surround the germ-line variety because it deals with future generations, rather than just the person receiving the therapy. On the basis of studies with model organisms it has been indicated that germ-line gene manipulation is technically easier to perform than somatic cell manipulation because "embryos incorporate foreign DNA and synthesize corresponding functional proteins more readily than most differentiated somatic cells." \(^{55}\)

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\(^{54}\) Canada, Medical Research Council of Canada, *Guidelines for Research on Somatic Cell Gene Therapy in Humans.*

Germ-line gene therapy has been successful in mice.\textsuperscript{56} The mouse zygote is injected with DNA and implanted into the oviduct of another mouse. The "transgenic" mouse develops with the new DNA in all of its cells. The technique has been used to correct a growth hormone problem in mice.\textsuperscript{57} R.L. Brinster concluded that micro-injection was of limited use because many of the mouse offspring did not live. There can be destructive results because micro-injection can badly damage the egg and because the DNA is integrated into the chromosomes at random. In 1983 this technique was questionable for humans as it resulted in a high failure rate, produced deleterious results and was deemed to be of limited usefulness.\textsuperscript{58} However, in 1989, a team of geneticists in Rome was able to produce a high frequency of transgenic offspring in mice. This meant that germ-line gene therapy would be a definite possibility in humans, as it was highly successful in other mammals.\textsuperscript{59} This is significant because germ-line gene therapy may be the only way to treat genetic disorders that are "not amenable to genetic repair after birth."\textsuperscript{60}


\textsuperscript{58}Anderson, "Human Gene Therapy: Scientific and Ethical Considerations," 284.

\textsuperscript{59}Suzuki and Knudtson, Genethics, 165.

\textsuperscript{60}Walters, "The Ethics Of Human Gene Therapy," 220.
Ethical Issues Regarding Human Gene Manipulation

Many questions are raised by these issues. Can we value and accept people who have debilitating diseases? What are our concepts of human dignity and worth and the value of the physically and mentally challenged? What warrants do we have to eliminate a disease from the genetic make-up because it is deemed abnormal? If the technologies are available, will they be made available to all of human kind, or only to those wealthy enough to buy them?\(^1\)

We are also faced with the possibility for misuse of genetic information. To cure one's genetic disorder, one's genetic information will become available. What does this mean to the idea of doctor-patient relations? Will the genetic information be divulged to outside sources? What if we find, through prenatal testing that our child will develop a debilitating disease at a particular age or through other diagnostic tests that we will develop cancer at age 30?

There are many implications that arise from genetic manipulation. Perhaps these procedures will be the great cure-all of the 21\(^{st}\) Century. However, we must first address the prevailing issues. Some of the issues raised by gene therapy concern the long-term consequences such as the efficiency of the therapy, how to rectify mistakes, risk assessment and decision making for future generations. "Is it prudent and responsible to make long lasting alterations based upon our limited knowledge of genes and of their full effects" even though we have done so in the past?\(^2\) As well, we must question whether the benefits for future

\(^{1}\)See Leroy Walter's article "Ethical Issues in Human Gene Therapy."

generations are overwhelming? Other issues that will also have to be considered are safety, "fairness in the selection of subjects," privacy, confidentiality, human freedom and free will.\textsuperscript{63} Further issues are whether human beings are, in fact, being manipulated, and the possibility that germ-line manipulation will be used for enhancement of an individual's genotype.

One could argue that through germ-line gene manipulation eugenic genetic engineering will be practiced. This is feared because it would involve the elimination of any unwanted characteristics from the human genome. The Council for Responsible Genetics (CRG) presents the idea that this type of activity would be very similar to the intentions of the Nazis and other Eugenics movements earlier in this century.\textsuperscript{64} Another point made in the CRG position paper is the statement that "any presumed beneficial effects of germ-line modification would pertain to individual families, not to the human population as a whole." The CRG suggests that the only way germ-line gene therapy could be effective for the human population would be over thousands of years and by forcing it upon people. However, it could be argued that this would depend on the objective of germ-line manipulations. Their final view on germ-line gene therapy, presented in their position paper is: "The [CRG] strongly opposes the use of germ-line gene modification in humans."\textsuperscript{65}

\textsuperscript{63}Walters, "The Ethics Of Human Gene Therapy," 215-221.

\textsuperscript{64}Council for Responsible Genetics, "Position paper on Human Germ Line Therapy," 35.

\textsuperscript{65}It is important to note that one of the references the CRG uses is: Paul Ramsey, \textit{Fabricated Man} (New Haven: Yale University Press, 1970). Ramsey is also firmly against gene therapy or any other genetic manipulation.
Although many of the concerns of Judeo-Christian theology are the same as those of secular society there are specific concerns that secular society does not address. J. Robert Nelson states that there is "no unusual theological or moral problem" with human gene manipulation. "Human germ line research is challenged on technical grounds and out of scientific consideration (the unknown impact on future generations), not on theological grounds."66 This notion is generally agreed upon and although the issues are not unusual theological or moral problems, specific ethical considerations that arise for theology are not excluded.

Human dignity and creation in God's image are two of the basic ethical issues that concern theology. Johannes Reiter states that when germ line therapy research is conducted on "human spermatozoa or ova the 'failures' cannot simply be set aside like seed plants. Human dignity lies in the fact that unlike the rest of creation human beings are created in God's image."67 However, Reiter does not mention that in sexual reproduction many sperm and eggs are not used in the creation of a single zygote. Are these sperm and ova failures? Other issues that arise for theology include the harm of future generations: "Is it a redemptive intervention or is it short sighted and likely to cause unforeseen and unwanted consequences?"68

Whether humans are unique is "essentially the theological question" because if humans are not unique, how can gene manipulation be wrong? The issue of the sacred status of human beings concerns the sanctity of human life,


which is an issue for secular society as well. Further ethical concerns include stewardship, evil, sin and moral mandates for justice and love.\(^{69}\)

Chapter Two: Theological Thought

This chapter deals specifically with religious thought from the Judeo-Christian tradition concerning gene manipulation and the Human Genome Project. The chapter is divided into three sections. The first deals with contemporary Jewish and Christian perspectives. The primary information for this discussion will be based on the most recent statements of Jewish traditions, Catholic, Anglican and the United Church of Canada. This information is important to discuss because it shows similarities and differences in the positions that these traditions hold. As well, current statements from the World Council of Churches (WCC) will be investigated. The WCC position is important because this group presents a collective position of many of the Christian denominations around the world.

The second section of this chapter deals with theological perspectives of genetic engineering. These perspectives focus on the early views of Rabbi Immanuel Jakobovitz (Jewish Orthodox), Joseph Fletcher (Protestant), Paul Ramsey (Protestant), Charles Curran (Roman Catholic) and James Gustafson (Protestant). Other theological insights on the topic under consideration will be derived from the works of writers such as Ronald Cole-Turner (Protestant), J. Robert Nelson (Protestant), Richard McCormick, S.J. (Roman Catholic) and others, who deal with these traditions and the subject from a theological perspective. An understanding of the early perspectives will provide a foundation for current stances on the issues.

The third section will involve the eliciting of select hermeneutical principles arising from the theological thought presented. These principles help to illuminate the ethical issues that arise. The hermeneutical principles developed will arise from the theologians drawing on their
rich traditions. Certain themes and symbols arise from these traditions, which help elucidate and give guidance to ethical decision making regarding gene therapy. The main themes, which serve as hermeneutical principles, that will be discussed are *imago Dei*, the sanctity of life, co-creation/co-responsibility and justice.

**Current Views from the Churches**

This section presents the most current statements of the Roman Catholic Church, the Anglican Church of Canada, the United Church of Canada, the Jewish community and the WCC. These views are intended to demonstrate an indication of how the Judeo-Christian traditions view the Genome Project and gene manipulation. These statements are derived from conference reports, working papers and Jewish *responsa*.

**The Roman Catholic Church**

Pope John Paul II has praised geneticists for their efforts in genetic research. In 1983, He addressed the issue of genetic manipulation asserting that the "biological nature of every human is untouchable in the sense that it is constituent of the personal identity of the individual throughout the course of history."\(^7^0\) In this statement John Paul II presents his basis for avoiding manipulation that will harm the origins of life. A more recent instruction from the Vatican indicates that it is acceptable to alter the human genome providing that the purpose of the alteration is not to create inadequacies in society.\(^7^1\)

\(^7^0\)Pope John Paul II, "The Ethics of Genetic Manipulation," *Origins* 13.23 (1983). All quotations of John Paul II in this section will be from this article unless otherwise stated.

John Paul II points out that any therapy or technology that can battle inherited disease should be permitted to progress. Any problems that arise for the Pope arise with the rights of humans, such as the right to life or health. He explains that all people who accept the Bible as Word of God share in the belief that the status of the human being is creation in God's image and redemption by Christ. These convictions may lead some people to a respect for human beings. To achieve this respect John Paul II expresses certain expectations. His expectations arise from the World Medical Association's 1948 guidelines for the Hippocratic Oath that state that physicians will "maintain the utmost respect for life from the time of conception; even under threat, I will not use my medical knowledge contrary to the laws of humanity."\textsuperscript{72}

What is expected of you is that you will attack the evil, attack what is contrary to life, but without sacrificing life itself, which is the greatest of goods and which does not belong to us. God alone is master of human life and its integrity.\textsuperscript{73}

Along with this respect for human beings comes the health care aspect of any gene therapy. Given such great respect for human life it is of utmost importance to recognize the patient as a person, aside from the technological care that is given.\textsuperscript{74}

John Paul II notes the importance of looking at the historical role of the physician. He emphasizes that the general practitioner had a knowledge not only of general illness but also of family history. Therefore it is important for doctors to recognize the whole person. A human is more than the sum of all inherent organs and systems. The organs work in conjunction with intellect and

\textsuperscript{72}John Paul II, "The Ethics of Genetic Manipulations," 387.

\textsuperscript{73}ibid.

\textsuperscript{74}ibid.
spirituality (388).

If these therapies are to respect human dignity they must "prevent any damage, then seek and pursue good" (388). Since it will be in the realm of the physician to initiate the therapies they will be aiding in the development of nature, rather than modifying it. John Paul II raises the question of how to reconcile genetic manipulation with the dignity of the human person. In regards to therapy that aims to heal various illnesses, it is certainly within the realm of Christian morality unless the intent is to alter personality. As well, some interventions that are outside the strict therapeutic sense, such as enhancement therapy, are acceptable. The Catholic viewpoint expresses a need to recognize the uniqueness of human beings. This uniqueness is expressed in the dynamic role of body and spirit. In order for these therapies to be within the realm of Christian morality they must recognize this uniqueness (388).

The Anglican Church of Canada

In its official statements the Anglican Church of Canada has made no mention of genetic manipulation or the Human Genome Project. However, they have made statements on biotechnology and various issues surrounding bioethics. The only place that reference is made to human genetics is in regards to abortion for genetic reasons. The Church is opposed to a "genetic defect in the fetus as automatic grounds for abortion."75

The fact that the Anglican Church of Canada has not made any sort of statement raises questions as to why. Other major churches have done so, why not this one? Do they regard gene manipulations as a potential problem? There appears to be no evidence that they do.

The United Church of Canada

The United Church has made several recommendations in regards to gene manipulation. They have not made an "official statement" but in a draft report they do raise several good questions and draw conclusions in several areas. Their recommendations are significant because they illustrate the church's concern with gene manipulations.

One of the questions raised in the United Church of Canada's draft report on gene manipulations is whether a set of common ethical principles exist that reflect the value systems of all cultures. It is stated that our view of medical ethics is "eurocentric." This raises a question of whether or not others will accept this value system. The United Church suggests that any decision-making concerning these issues be conducted by groups that consist of people from all facets of society. As well, they assert that any counseling facilities be staffed with people who can translate the "scientific language to lay persons during the informed consent process."

Their recommendations suggest that societal interests are toward the individual. They ask "do the interests of the individual necessarily override the interests of a larger society in respect to potential harmful impacts on

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76 United Church of Canada, "Draft," (Etobicoke, Ontario: United Church of Canada, 1992). This is a draft assessment of a study guide on the ethical issues of gene manipulations.

77 Ibid, 4.

78 Ibid, 2-3.
the existing gene pool?" This question surrounds a number of issues and raises several questions in itself but they do not make any conclusions.

The recommendations they make concern the following areas: funding and research, access to treatment, mistakes, germ cell transfer, enhancement, the gene pool, procedure for research proposals, unethical conduct and universities and pharmaceutical companies. The problem that arises with these suggestions is that they are vague. The following is an outline of the United Church of Canada's questions and recommendations:80

1. Privately funded projects undergo the same ethical guidelines as publicly funded ones.
2. Can gene therapy be distributed equally? Due to high costs it may limit universal treatment.
3. Who is responsible for mistakes? Is sterilization an option when these mistakes are made with the germ line?
4. Germ-line therapy should not be permitted with present knowledge.
5. The United Church is opposed to enhancement of the phenotype.
6. Genetic defects should not be eliminated as they may hold an adaptive feature scientifically unknown.
7. New proposals for research proposals should first be accepted at a local level and then a national level.
8. Those who participate in unethical experiments should be barred from research.
9. Both pharmaceutical corporations and universities should have to go through the procedures of the local and national review boards.

Jewish Communities

Judaism offers a perspective that comes from various sources. Rabbis from different Jewish perspectives; Reform, Orthodox, Traditional, etc., make statements that reflect the views of their particular tradition within the Jewish community. As well, Jewish statements are derived from responsa literature.81 Given the various responses Judaism

80These recommendations are not an official statement but are the result of comments and assessment of the Medical Research Council of Canada's Guidelines for Research on Somatic Cell Gene Therapy in Humans.

81This information was obtained in a conversation with Rabbi Jeff
may offer there is no "official" position. In this thesis various Jewish positions are drawn from when examining the theological discussion on the issues of gene manipulation and the Genome Project in Chapter Three.

The World Council of Churches

The World Council of Churches is a federation of member churches consisting of most Protestant and Orthodox churches around the world. With its base in Geneva, Switzerland, the WCC deals largely with maintaining ecumenical unity. The initial mandate of the World Council was to relate the Christian faith to social issues. The WCC attempts to continue this task through regular assemblies around the world. It is because of the mandate to relate the Christian faith to social problems that the WCC is important to this research.

In 1970 it was agreed by the WCC that new discoveries in genetics would require close attention of the churches. This initial concern resulted in the book *Genetics and the Quality of Life*. This book was presented to the WCC Assembly in 1975 and prompted further study in this area by the member churches.¹² The most recent outcome of these extended talks on the issues surrounding genetic technology is the report *Biotechnology--Its Challenges to the Churches and the World*.¹³

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¹²World Council of Churches, *Manipulating Life* (Geneva: World Council of Churches, 1982), 11. By the 1980's the WCC was urging the guarantee of protection of human subjects in genetic research, suggesting that review bodies for research are generally made up of those with vested interests. They also recommended that women and minorities play an integral role in decision making concerning eugenics.

This report makes one simple recommendation concerning gene manipulations. They recommend a ban on experiments involving genetic engineering of the human germ-line at the present time, and encourages the ethical reflection necessary for developing future guidelines in this area; and urges strict control on experiments involving genetically engineered somatic cells, drawing attention to the potential misuse of both techniques as a means of discrimination against those held to be "defective" (14).

This recommendation does not shed a great deal of light on the ethics of gene manipulation and the Genome Project but the WCC does promote the voice of its members.

The report also addresses the potential technologies that will arise from mapping and sequencing the human genome. They make three recommendations in this area. The first is that genetic testing for sex selection should be prohibited, claiming that this is a form of "social engineering." The second recommendation is simply a concern for the potential abuse of the genetic make-up of individuals becoming a form of discrimination. The third recommendation is that the WCC "stresses the need for pastoral counseling" for people who are faced with decision making based on genetic concerns (12).

The final response of the WCC to the Genome Project and gene manipulation is based on faith in "God's intentions for the future of the life of the world" (30). The WCC asserts a principle of justice and indicate that the justice of God is denied when genetic knowledge is used to make rich nations richer, when it is used for discrimination and when women are exploited. Creation's integrity is wronged when it is used for commercial interests, when the diversity and uniqueness of humans is threatened and when new organisms are "released into the environment irresponsibly" (30). In light of these potential obstacles, genetic technology has the potential to increase insight of the way in which all life is connected and to further the reach of the "arts and ministry of healing." The WCC maintains the goodness of
Creation and essentially asserts that genome research and gene manipulation will bring all of Creation closer together (30).

Theological Thought*

This section deals with theological views on gene manipulations. First I survey early theological views on the subject because they provide a rich foundation and give further discussion a more pointed direction. Further theological insights on gene manipulations arise largely from reflection on the thought of the early theologians. The significance of further discussion is to provide background for my own theological views. My view of human nature, co-creation, is closely related to James Gustafson's perspective. Given that Gustafson does not discuss gene manipulation in any great detail I turn to other theologians to aid in further expressing my theological tendencies.

Rabbi Immanuel Jakobovitz: An Early Jewish Orthodox Perspective

Immanuel Jakobovitz disregards the potential for genetic technology but indicates the deeply rooted role, and awareness of, genetics in the Jewish traditions. He does not deal directly with genetic technology but his Jewish Orthodox point of view does have aspects that are purely concerned with passing deleterious genetic qualities to future generations. Genetics falls under the terms of eugenics, sterilization and contraception in Jakobovitz's book *Jewish Medical Ethics*. He states that issues concerning genetics demand a "reliable evaluation of life, in absolute as well as relative terms - a task altogether

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*In this section, the typologies of Joseph Fletcher, Paul Ramsey and Charles Curran and James Gustafson are derived from: Michael Fallon, *The Ethics of Genetic Control* (Toronto: St. Michael's College, 1975).
outside the purview of medical science."\textsuperscript{65}

For Jakobovitz genetics is very closely related to marriage and procreation. Jewish law promotes striving to eliminate deleterious genetic qualities from a family lineage. The goal of Jewish eugenics is the "pursuit after the most numerous and physically, mentally and morally sound natural increase of the people, without thinking of an exclusive race protection."\textsuperscript{66}

To achieve their genetic goals Jewish law places an emphasis on choice of marital partners. People are encouraged to marry the most highly intelligent and morally virtuous partner they can. As well, it is discouraged that one should marry into a family with a history of any hereditary disease. Jewish law requires that women and men alike are to have a physical exam before marriage, so any physical defects can be recognized.

Jakobovitz emphasizes the importance of genetics in Jewish law. The importance lies in a responsibility towards society and future generations. The aim is to create safeguards against "contracting crippling or deadly afflictions and in protecting society from an avoidable increase in physical and mental disabilities."\textsuperscript{67} Jakobovitz indicates that sterilization is forbidden in women, men and animals. The reasoning behind this inherent Jewish condemnation of sterilization is stated in the Talmud:

It is forbidden to impair the reproductive organs, whether in man or in domestic animals, beasts or birds, whether these are clean or unclean..., and whoever performs a castration transgresses a biblical offense and he is liable to corporal punishment.\textsuperscript{68}


\textsuperscript{66}ibid, 155.

\textsuperscript{67}ibid, 158.

\textsuperscript{68}ibid, 162.
For Jewish law it is a basic assumption that couples be fruitful and multiply, as God has given them the opportunity to do so. Sterilization can only take this opportunity away.

Rabbi Jakobovitz expresses the ideal of a thoroughly genetically aware community when he speaks of the Jewish eugenics. Even though Jewish law did not include genetic technology, Jewish communities expressed notions of dealing with deleterious genes that other traditions did not deal with (Jakobovitz mentions the Catholic tradition). Little can be drawn from this early perspective on how to deal with genetic technology and research. However, there is a great deal to be learned from Jakobovitz’s treatment of debilitating diseases. This early Jewish notion offers an example of "non-techno" genetics. Jakobovitz’s ideas express the direct importance of eugenics that both Paul Ramsey and Charles Curran advocate. I think the primary lesson to be learned from Jakobovitz’s work is that the human genome can be altered without the use of expensive, ethically plausible, technology.

Joseph Fletcher: Self-Creation

Protestant theologian Joseph Fletcher had a very positive view of genetic engineering and the genetic technology that goes along with it. He advocates the notion that "to be civilized is to be artificial," claiming that artificiality is a human hallmark.\(^9\) It is through artificial means that humans proceed in the "natural" world.

\(^8\)By "non-techno" I mean that Jakobovitz's portrayal of Jewish eugenics using no industrial technology. Their genetic plan is geared towards rudimentary selective breeding or simple reproductive choices, as opposed to the variety of genetic technologies we have available to us today.

\(^9\)Fletcher, The Ethics of Genetic Control, 15. I interpret Fletcher to mean that humans create by their own means without the help of God.
This was the premise of Fletcher's anthropology; the human as self-creator.

God had given us reason, transforming us from creatures to creators. Because of our status as creatures we are left to make the responsible choice for genetic technology that Fletcher advocated. To him it came down to a matter of sanity. It would be insane to stop genetic technology because that "is where we are going, and where we ought to go" (199).

One way to describe Fletcher's point of view is the argument of "chance vs. choice." What this comes down to is that we can leave genetics to "natural" chance or we can make responsible choices in the matter. For Fletcher the responsible choice is the rational control of genetic technology. One reason that Fletcher gives for his positive attitude towards genetic technology, including gene manipulations, is that "a people with fewer defects and more control over the crippling accidents of "nature" are better able to master life's ups and downs" (13). Because science is powerful:

> the uses to which this power will be put in human affairs involves choices and decisions, that is, value judgments. This implies a special responsibility of scientists; that of informing the public of the actual and potential application of their findings and of the possible consequences (198).

Many of Fletcher's fellow theologians argued against genetic technology on the basis that there would be a great deal of risk and the possibilities for error. He responds to this by arguing that:

> risk and error are always given factors; they exist in the very finiteness of things. And the point about artificial control is precisely that it tends to reduce risk and error, and is intended to do so (96).

As well, he argued that genetic engineering would cut medical costs because of its potential to fix the problem at its cellular source. In terms of purely theological arguments against genetic technology, which were seriously
concerned with conception and birth questions, Fletcher responds with the question "if creation in God's image is a duty, then why can it not be fulfilled by artificial means just as well as by natural ones?" (96). This question is answered by Fletcher with a simple 'yes it can be done.' The basis of this conviction was that the Virgin birth is not unique because the Virgin Mary would have to have been impregnated by sperm because only the male sperm can supply the male chromosome (106).

He pointed out that what is right or wrong cannot be determined before the fact. We cannot tell if the Genome Project or germ-line manipulation is right or wrong until after they have been tested on humanity. He holds the position that if we are to use technology to solve problems and it causes subsequent problems, we must use technology to solve those problems too (191).

Not many of Fletcher's contemporaries advocated genetic technology. He was determined to portray genetic engineering, and respond to other theologian's fear and loathing, with "down to earth" views. It appears that he had a very good sense of the constant flux that occurs in life. In terms of theological opinions he implied that "old precedents and packaged answers that were built upon the old folklore of life" must be refurbished if the thought of theology is to leap forward and be persuasive in its arguments (194).

Paul Ramsey: Steward of Creation

Another Protestant theologian, Paul Ramsey argues that it is unethical to create unless it is through procreation, in the image of God. This is due to the covenant between God and humanity described in the Old Testament. Ramsey is concerned that through genetic engineering humans will alter God's creation. For the Christian this is important, but
for the non-Jew or non-Christian *imago Dei* means little.

Ramsey's notion of anthropology depicts humans as stewards of God's creation. Ramsey discusses two aspects of human nature: 1. the human relationship with humans and 2. the human relationship with God. As stewards of God's creation human dominion does not include dominion over the human body nor does it allow for the separation of procreation and humanness. The human relationship with God indicates that humans must maintain their role as animals rather than gods.

His basic assertion is to stop all research in the area. For Ramsey the notion of "choice vs. chance" is that it is better to not take the chance and be safe than to make a choice for genetic technology and become dependent on it. Although he does acknowledge a need for genetic control, he sees it as a choice between voluntary, selective breeding and gene manipulation. He advocates selective breeding, using the example of success that Jewish communities portray with Tay-sachs disease.

When he wrote *Fabricated Man* in 1970, there was a lack of knowledge in the area of genetic science compared to the present day. He states that this lack of scientific knowledge and "the enormous practical obstacles in the way [of genetic technology], ought not to be given important place in a discussion of the moral and religious issues raised by present and future eugenic proposals."\(^{31}\) I refute this as being ludicrous. How could we possibly disregard scientific knowledge, whether an abundance or the lack thereof, when discussing the morality of a subject so intricately tied to science? Ramsey also indicates that scientists may describe humans in a way that neglects important aspects of human nature, only describing them as

\(^{31}\)Paul Ramsey, *Fabricated Man*, 2.
with the characteristics of scientists (22). Ramsey's view towards science implies that the ethics of science is a "fruit of intending the world as a scientist, and not expressly from intending the world as a man among men" (22). Later he indicts scientists as being poor architects of social policy. He attempts to express that there is much more to being human than the scientist, carpenter or athlete: expressed in their personal world views. Scientists may not be the greatest architects of social policy but the question is are social policy makers the best suited to making policies based on science?\(^2\)

Ramsey presents a position that Christians cannot procreate outside of God's intended means without refuting the notion of *imago Dei*. His thesis rests on this notion. Through preventative eugenics humans avoid doing God's will, or God's intended duty, at the same time preventing untold misery for future generations.\(^3\) Further discussion on this point brings out an important challenge: what we should do as opposed to what we can do. In other words, we are limited in our choices concerning genetic abnormalities. If this is the case then we can never be freed of genetic disease because it would not be God's will. This has some scientific truth because even if germ-line manipulation was experimented on humans, it is quite possible that mutations would occur to alter the effects of the manipulation. Ramsey states that "where there is no God, then self-modifying freedom must be the man-God" (93). Therefore man is now creator with no respect for Creation.

\(^2\)Angus McLaren, *Our Own Master Race: Eugenics in Canada, 1885-1945*, (Toronto: McLelland and Stewart Inc., 1990). McLaren discusses the history of eugenics and sterilization in Canada. His discussions include the making of sterilization policy and eugenics plans. As well he looks at the basis for the Nazi experiments and policies.

\(^3\)Ramsey, *Fabricated Man*, 57.
What Ramsey's point of view really comes down to is his view of human nature or anthropology. What does it mean to be human? Are we creature or creator? He concludes that "men ought not to play God before they learn to be men, and after they have learned to be men they will not play God" (138). From a Christian perspective hope in the future does not depend on genetic mutation where a scientific eschatology, or view of 'last things,' places human nature in jeopardy. Ramsey asserts, optimistically, that "God means to kill us all in the end, and in the end He is going to succeed" (27).

Even though Paul Ramsey presents a very unfavorable perspective of genetic technology, he does assert the unique stake that Judeo-Christian thought has in the future of humankind: without the covenant between God and humans, we are not just creatures, we are pseudo-gods (93). As well, he presents a positive argument for an alternative to genetic technology and gene therapy; selective breeding on a voluntary basis which would essentially mean to breed out unwanted characteristics rather than remove them in a clinical setting. It has been practiced in history and he believes its use can aid us in maintaining the covenant with God. Another assertion he makes is that we can continue without the use of genetic technology. In conclusion, Ramsey presents a view that through genetic engineering humans would be "playing God." He responds to this by saying "only God could know enough to hold the future [of our genes] in His hands" (131).

Charles Curran: The Catholic Moralist

Although Charles Curran is a Catholic moral theologian he is no longer permitted to teach as one. However, his views on genetic technology have been developed from the point of view of Catholic moral theology. He bases many of
his points on Paul Ramsey's opposition towards genetic technology. The basis for this adversity is found in the early dialogue on the ethics of genetic engineering; there was a great deal of concern over the morality of the means, rather than the end result, of genetic engineering in the future. The difference in their conclusions, however, is that Curran appears to realize the extent to which scientific and technological advancement is assured; he says that we will have to be careful in accepting genetic research and technology but that is no reason to stop research.

Curran's notion of human nature reveals humans to be experiencing constant change. They are capable of self-creation through their technological knowledge. However, because of their status as animals they do not have full control over creation of human life. They are co-creators to the extent that they can balance being creaturely and having creative power.

Curran presents three areas that theology would have to concentrate on in an approach to these issues. A heightened appreciation of historical consciousness is necessary to expand the notion of anthroplogy. It is his idea that if human nature is viewed as a closed door, as "something already within the self to which the individual must conform oneself and one's actions will be an inaccurate understanding of human reality and tend to result in unacceptable moral conclusions." He also advocates the importance of a communitarian approach, rather than an individualistic approach, to gene manipulation. He implies that the individualistic method does not include the social

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²⁴To self-create means to create without God's assistance, direction or permission.

aspects of reality (114).

Curran encourages the need for a balance between the two. "Moral theology cannot employ models that are exclusively individualistic or narrowly interpersonal" (114). Models that draw from a broad social perspective have to be employed.

The third concentration would be in the area of human dominion and power over life. Even though science affords us greater dominion over our lives, the Christian must remain aware of the status of creature and sinner. "Biology or genetics will never completely overcome inherent human limitations and sinfulness" (124).

Curran’s approach is aimed at creating an awareness for moral theologians; an awareness of how to deal with the genetic technologies that we are faced with today. Curran's perspective draws from the optimism of Joseph Fletcher and shares the cautions of Paul Ramsey. As well as the three areas moral theology should become aware of, Curran presents three dangers to be aware of when dealing with the genetic technology.

The first of these dangers is the attainment of a utopia. Curran makes it clear that Christians, better than anyone, should be aware that utopian ideas are not feasible. He suggests that this was made clear with the Social Gospel movement (124). Eliminating all deleterious genes may be a possibility scientifically but this type of perceived utopia is not feasible for the Christian. This raises a question of whether or not Christian moral theologians still put faith in the possibility of reaching some sort of utopia.

A second danger he implies is that humans empower science by allowing it to direct society, meaning that as we place a greater emphasis on science it will have increased power (127). This involves a scientific imperative: because we can achieve our genetic goals does not mean that we
should. Along with this he argues that those who see the world through the eyes of a particular science do not allow for the input of other facets of society. He uses the example that sociology would assert the importance of family and marriage, while the geneticist may disregard these in pushing for genetic technology (129).

The third danger that he discusses, along with Fletcher and Ramsey, is the "dominion and the power which one has over one's life." He observes that humans have a greater and greater control over their destiny as technology progresses. For Curran, humans play the role of steward of God's gift of life. The danger arises when this dominion over life is not used responsibly. Curran places less emphasis on this particular point than Ramsey does.

The message that Curran appears to be sending is that we have to be careful when proceeding with genetic technologies. He presents his fears but does not exclude gene manipulations as a possibility. He implies that our increased knowledge of our genes will help us in the future.

Development of Hermeneutical Principles

In this section I will illustrate the hermeneutical principles that will be used as a basis for responding to other theologians in the discourse on gene manipulations and the Genome Project. These principles are derived from themes that have arisen in the positions of the theologians and churches and support my own theological views that I presented in the introduction.  

\textsuperscript{96}ibid, 119.

\textsuperscript{97}ibid, 121.

\textsuperscript{98}I believe that God has given me life and because of this my life is sacred. To fulfill God's role for me I must work with God in the creative endeavor. This means that I do the things that I do for something greater than myself; there is a higher purpose than life itself. In doing this I have responsibilities. Part of this
The first theme that I focus on is the notion that human beings are created in God's image and act as co-creators with God. To express the idea of co-creation I examine James Gustafson's view of human nature because I think it closely resembles my own. I will expand on the notion of co-creation with the help of Ronald Cole-Turner and other theologians who also express this notion in their work.

Next, I examine the sanctity of life which is closely related to the doctrine of *imago Dei*. I attempt to define the sanctity of human and its role in ethical deliberations such as gene manipulation. I establish a Judeo-Christian notion of human sacredness that is rooted in *imago Dei*. I also discuss *agape*9 in the sense that it ought to be part of an ethic for gene manipulation.

The final theme that I develop as a hermeneutical principle is justice. I argue that justice results from human rights. These rights can be based on human dignity, which can arise from *imago Dei* and the sanctity of life. Unlike some theologians, such as Joseph Fletcher, I argue that justice and *agape* are separate.

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9James F. Childress, "Love and Justice in Christian Biomedical Ethics," in *Theology and Bioethics* E. E. Shelp, editor (Boston: Kluwer Academic Publishers):225-243. Childress offers four definitions of *agape*: 1. seeking the neighbor's welfare; 2. self-sacrifice; 3. mutuality; 4. equal regard. If we follow the thought of James Gustafson we can elicit another definition of *agape*. This definition is based on the idea that all things are interdependent. If we have a "co-relationship" with God, then we have a "co-relationship" with human beings. Just as God is responsible for all human beings within this relationship, all human beings within this relationship are responsible for each other. *Agape*, then, can be defined as responsibility for our interactive relationship in the universe. Thus *agape* is carried out through human action.
I think that where there is no love there can be justice but love will arise from doing just things, such as caring for a child with a severe genetic aberration.

James Gustafson: A Basis for Change

Although James M. Gustafson does not play a large role in the discussion concerning gene manipulations he offers an opportunity for a different view of human nature. We have seen Fletcher's 'no holds barred' approach revealing humans as self-creators, as well as Ramsey's finitely conservative view of the human as steward; both of these views indicating extremes. In between these outer limits Rabbi Jakobovitz and Charles Curran present more permissive but cautious views on genetics and human nature. Gustafson's anthropology falls in the center of these positions. As well, it presents a foundation for a discussion of co-creation.

Perhaps the most significant aspect that comes to light in Gustafson's early reflection on genetic manipulation is the view of the normatively human. This is significant in considering gene manipulation because Gustafson indicates that we ought not even begin thinking about gene manipulation if we have a definitive image of the human in mind. Instead he suggests that we ought to place a great emphasis on the notion that the human has initiative and freedom to "explore, develop, expand, alter, initiate, intervene in the course of life in the world." This freedom is extended to the human life. Gustafson has also clearly stated that guidelines for research and the execution of gene manipulation ought to be set.

However, these guidelines should not be intended to "set certain limits beyond which [humans] cannot go."\textsuperscript{101}

Considering these notions it may be profitable to gain a further understanding of Gustafson's anthropology. Michael Fallon's interpretation of Gustafson's anthropology presents ten characteristics of human nature. The ten characteristics are:

1. Capacity for exploration, intervention and self determination
2. Notion of vocation
3. Human physical life
4. Suffering as a relative of mitigated good
5. The human capacity for knowledge
6. Personal freedom
7. Trust
8. Relationship of love
9. Open yet critical response to knowledge concerning human behaviour derived from the social sciences - the degree to which human behaviour is determined, functionable and researchable.
10. Capacity to respond, to govern one's actions in accordance with the decisions and purposes\textsuperscript{102}

I would break this list of characteristics derived from Gustafson's view of human nature into three basic points: 1. the natural human; 2. human fault; and 3. correction.\textsuperscript{103}

\textsuperscript{101}Ibid., 285.

\textsuperscript{102}Michael Fallon, *Ethics of Genetic Control*.

\textsuperscript{103}These groupings are derived from: James M. Gustafson, *Ethics from a Theocentric Perspective Volume One: Theology and Ethics* (Chicago: The University of Chicago Press, 1983). The following is an explanation of these groupings derived from the stated text.

The natural human depicts three things. The first group involves dependence and interdependence. Dependence acknowledges the limitations and possibilities for human initiative and development. Interdependence "reflects more the interactive relationship between human life and activity and the rest of the world" (283). In relation to God, human beings are dependent in the sense that God has a set order for all of creation including human initiative. Interdependence arises in the human relationship with other humans or how human beings fit into God's ordering of all creation.

The second aspect of the natural human is that we place value on things, meaning that we are capable of choosing which values we ought to pursue. Not only does it indicate that we are capable of determining which values we ought to choose, it suggests that we are capable of defining which values are more important than others.

The third group indicates that human beings are agents. This means that we have power other than that which God has ordered. We can affect God's order (287).
Gustafson's appraisal of human nature presents human beings as being both dependent and interdependent. Dependent in the sense that God has a certain order for us to fall into and interdependent in the sense that we interact with all

Human fault involves the human "tendency to be turned inward toward ourselves as individuals, or towards our communal interests" (306). There are four aspects to human fault: 1. trust and loyalty; 2. desires and loves; 3. corruption of rationality; 4. disobedience.

Our sense of trust and loyalty is constricted by idolatry. The term idolatry is defined by Gustafson as "objects of ultimate trust or confidence that do not and cannot bear the weight of reliance that we place upon them for providing sustenance and meaning" (295). Gustafson indicates this obsession with trusting persons, institutions, and values clouds the "proper relationship among these things" (305). Because we have this misplaced trust we have a distorted sense of loyalty. "We become insensitive to the needs of other persons, other groups, other nations, and even of nature by the contraction of our desires, by an undue focus on the individual self, on one's family or nation, or on one's profession or institution as the object of love" (304). Our desires and loves then are misplaced.

The corruption of rationality arises from the assumption that there are no boundaries in our ways of knowing, conceptualizing, our procedures for making judgments, and the reasoning behind our choices. The corruption arises when our human vision is narrowed, leaving us "unwilling to imagine other ways of ordering experience, other ways of relating aspects of knowledge to each other, other contexts in which what we know can be interpreted" (304).

The final aspect of human fault is disobedience. Simplified it is an obsession with what is beneficial for the individual. This is very much in line with misplaced desires and loves which result in an insensitivity towards other people, places and things.

The final part of Gustafson's anthropology is correction. While human fault is seen as a narrowing, correction is deemed an expansion and enlargement of the human vision. It is also an enlargement of the "ordering of the heart," aimed at correcting disobedience.

To enlarge the human vision Gustafson proposes reassessing tradition both culturally or religiously. This entails relating all things to the human relationship with God. This enlarged human vision asserts that human perfection is impossible to establish because humans are constantly changing. What is essential to this expanded vision is situating a place in the universe.

This place in the universe is revealed in Gustafson's "ordering of the heart." The premise of this ordering is theocentric piety. It "enables an enlargement of affections and loyalties, and an ordering of them under divine governance" (315). This reordering of the heart involves embracing other creatures and their well being, rather than having a selfish mentality. This reordering is never complete because human interaction is dynamic and always changing.

Correcting disobedience can also be based on this theocentric vision. It involves taking risks and acting unjustly, at times, for wider justice, nor does it relieve the human experience of the possibility of human tragedy. Gustafson summarizes this point by saying that "human agency based on our distinctive capacities expands our causal accountability beyond the well-being of the human life to the well-being of various 'wholes' of which we are parts" (317).
things in creation. His anthropology also indicates that human beings pursue particular values and can choose which values to follow. As well, humans are agents; meaning that we are capable of altering our intentions to affect the course of events in creation. "Our actions are directed by our purposes, and different conditions are necessary for different purposes."104 Further characteristics indicate that humans have a misplaced sense of trust and value, a corrupted rationality and are disobedient. These faults can be corrected through a widened vision. This widened vision allows humans to be released from individualism and focus on things beyond the spectrum of humanity.105

Gustafson's view of human nature indicates that we share the responsibility of creation with God. This is significant to this study because the theological perspective presented is based on the notions of co-creation and co-responsibility. To gain further understanding of these concepts I will look at theologians who have also developed co-creation and co-responsibility.


105 This discussion is intended to elicit a furthering understanding of Gustafson's anthropology in light of the notion of co-creation. In terms of Fallona's characteristics it may help to simplify them. For example, Gustafson's notion that the human is an agent is summarized in Fallona's interpretation of the human capacity to explore, intervene and determine their own path, as well as in his notion of human freedom and capacity for knowledge. The human agent has the power to intervene or manipulate life in any way it is capable. Humans have the capacity to alter life in terms of human intentions and ends. This does not mean that the manipulation is right of course. This notion of agency would include Fallona's second characteristic, Notion of vocation. Humans may have the capacity to make these changes but they must also have a purpose. This purpose is their vocation.
Further Theological Insights: Co-Creation and Co-Responsibility

This section will develop the notions of co-creation and co-responsibility developed in the last section. One concern of Christians is the role of humans in nature and creation. What is the relationship between God and humans? For the Judeo-Christian community this relationship involves being created in the image of God (imago Dei). This is relayed to believers in the book of Genesis. The relationship is also based on the covenant between God and the people that is portrayed in Exodus. God shows the people a new land where they can prosper. This indicates the notion of stewardship.

In the biblical account God creates humans, giving them rational faculties and dominion over all other species of animals and plants.\(^{106}\) This is the theme in Genesis but in Exodus there is a shift. Agriculture becomes important. With this dominion over other species humans saw themselves as agriculturists.\(^{107}\) Ronald Cole-Turner indicates that this is significant because the people were able to recognize that their relationship to the land was "based on their relationship with God."\(^{108}\)

But does this mean that humans have dominion over themselves? Paul Ramsey's anthropology introduces a two-fold view of human nature that advocates stewardship. The first part concerns the relationship between humans and themselves. The second involves the human relationship with God. The human experience has two conditions: 1. humans do not have dominion over their own bodies; 2. procreation and

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\(^{106}\) Psalms 8.5-9


\(^{108}\) ibid, 343.
humanhood are not to be separated. The human relationship with God requires humans to maintain a creaturely status. On the other end of the spectrum is Joseph Fletcher's anthropology that indicates that humans are self-creators. With their knowledge of technology they are capable of self-manipulation. Because of this potential for self-change human dominion is self-controlled in light of *imago Dei*.

Ronald Cole-Turner claims that humans ceased to be stewards of God's creation, becoming co-creators.\(^\text{109}\) This is one of his fundamental arguments. He claims that gene manipulation is a form of co-creation with God. Cole-Turner suggests that if we envision ourselves as co-creators with God we "must have some sense of what God intends."\(^\text{110}\) He argues that in *Genesis* we are given dominion over all life. If God intends humans to be kings of the earth then we certainly have a sense of God's divine intentions. We are enthroned with the power to create.

Gustafson's notion of the human as an agent backs Cole-Turner's argument. Creation is in God's image and as agents humans also have this power to create. Gustafson is very clear in stating that human initiative is what gene manipulation rests upon. Humans are free to explore and intervene in anything they choose to intervene in, including their own lives.\(^\text{111}\)

The notion of co-creation lends a significant twist to the ethics of gene manipulation. If neither humans or God dominate all of creation one could speculate that they must be working together. This implies that God still has an active role in the creative process. God created humans with the ability to create on their own.

\(^{109}\text{Ibid, 346-347.}\)

\(^{110}\text{Ibid, 338.}\)

\(^{111}\text{James M. Gustafson, *Theology and Christian Ethics*, 285.}\)
It is much like a child learning to ride a bicycle. At first the child uses training wheels and the parent watches closely that they do not fall. Soon the child is riding well on their own and wants to be free of the training wheels. The parent removes the training wheels and runs along, stabilizing the child's bike for a few yards until the child has the momentum to ride on their own. God started the creation ball rolling. God helped to get humans started in creation by giving them the ability to create. As time goes by they have increased momentum in their creative endeavor but God still watches over, ready to stabilize the situation if something should become unbalanced. Like a parent teaching a child to ride a bicycle, God has helped humans learn to create. I would suggest that if, in light of human technological prowess, God is taking part in the creative process then we can consider the human relationship with God as nothing other than co-creation.

For a Judeo-Christian community it is important to embrace the belief in *imago Dei* as well as the covenant with God because these beliefs ground these communities. Jews and Christians are created in the image of their God and they have a special relationship with this Creator. Rather than being creatures or lords of God's creation they are involved in a pact with God. This idea is amplified by Gustafson's view that humans have the capacity to affect the outcome of events. The story may go something like this: God creates the world and all of its creatures, including humans. Humans are given rational faculties and through their own initiative begin to create beyond the means given the creatures by God. This ability to create beyond the given means is a part of God's ordering. Human freedom allows the opportunity to choose to do this. In choosing to create by these means humans are doing two things. The
first is that they are affirming their dependence on God's order. The second is that they are affirming the idea that they will attempt to do whatever they are able to do and this ability will broaden with increased knowledge of life.\footnote{Ibid, 285.}

Ronald Cole-Turner, a Protestant theologian, suggests that the advancement of genetic knowledge has created a challenge for the world of Christian theology. He argues that:

Christianity has assumed that all are morally and spiritually equal. All have sinned, all stand in need of grace, and all have the same moral capability, and all are equally responsible for their behavior. Thanks to research in human genetics, we are learning that this presumption no longer holds.\footnote{Ronald Cole-Turner, "Religion and the Human Genome," \textit{Journal of Religion and Health} 31, no.2 (1992): 171.}

Cole-Turner argues that as we increase our knowledge of the human genome we will see how each of us are increasingly individual. With this increased sense of individuality we will have to personalize morality and spirituality. "Individual differences must be affirmed, not discriminated against. They must be comprehended theoretically and theologically, not rounded off statistically and ignored pastorally."\footnote{Ibid.} This shift to the individual is a concern that was also raised by Charles Curran.

How will we manage to focus on the community while we are becoming more and more aware of our individuality? I think this is an important question to consider in light of our increasing focus on individual differences. Each of us is biologically unique but I think that on a spiritual plain we are all viewed by God as equal. I do not think that the Genome Project or gene manipulation change the Judeo-Christian notion that we all have sinned, that we all have
similar moral capabilities or that each of us, as individual as we may be, are responsible for our behaviour.

We can see from Gustafson's perspective that the interdependent relationships within the universe indicates the importance of dealing with individuals. We ought to consider how individuals relate to the larger vision. If we focus on individual differences we are bound to give meaning to categorizations such as 'equal or unequal.' In light of the potential for an increased sense of individualism, we ought to keep the interdependent nature of our existence in mind.

Contrary to Cole-Turner's suggestion that gene manipulation is co-creation, Rabbi Moses Hershler suggests that changing the divine genetic make-up shows our lack of faith in our Creator.\textsuperscript{115} However, Cole-Turner holds that because God was aware of His divine intention to create humans as co-creators, we must also be aware of these intentions in our creative enterprises.\textsuperscript{116} Gustafson indicates that God's ordering of life through natural processes may be a basis for "understanding what is valued about life [and] what ought to be valued about life."\textsuperscript{117} Our role as co-creator takes on a greater theological meaning when we look at research in this manner. If theology has a stake in the research, i.e., understanding God or human nature, then the research and therapy should be of importance to theology. Not only do we stand to gain a


\textsuperscript{116} Cole-Turner, "Is Genetic Engineering Co-Creation?," 345.

further understanding of humans but we may gain insight into "how God is ordering life in the world, and even in some cases something about God."\textsuperscript{118}

Cole-Turner suggests that humans are in need of taking responsibility in a new awareness of the role of co-creator. This entails a sense of co-responsibility. Gustafson says that "God will be God; God will not be denied."\textsuperscript{119} God is well aware of the responsibilities that go along with being God but humans are not always aware of their responsibilities. We must have faith in our role as co-creator. If believers lose faith in God, they will become pseudo-gods, taking on responsibilities they are not aware of. Humans need only recognize the limitations of their creative abilities. If we do not recognize these limitations with gene manipulations there is the potential to alter the human genome and the universe in irreversible ways. We ought to keep in mind that God, like a responsible parent, watches over our creative capabilities but the responsibility is only partly God's. If we mess up we can't go blaming God! What we can do is allow our relationship with God to "empower our imagination and restrain our foolishness."\textsuperscript{120}

J. Robert Nelson introduces a "realist" approach to human nature that indicates humanness is defined by being created in God's image. Nelson indicates that if Christians are seperated from their notion of Creation they will not be in the image of God. James Gustafson comments that this is part of an ethics of restraint. He states that the

\textsuperscript{118}ibid.

\textsuperscript{119}Gustafson, \textit{Ethics from a Theocentric Perspective Volume Two}, 296.

\textsuperscript{120}Cole-Turner, "Is Genetic Engineering Co-Creation?," 349.
perception of the image of God can determine its utility as favoring or opposing "possible interventions."\textsuperscript{121}

Nelson divides gene manipulation into two categories: medical/therapeutic or eugenic/political. He argues that the first category is of the variety that will heal disease, while the second choice caters to those who wish to enhance the phenotype of a group of people.\textsuperscript{122} Somatic cell manipulation has been tested with successful results which in Nelson's view is a positive outcome. Germ-line manipulation in humans is likely to proceed in time, with a good deal of caution. This is similar to Gustafson's view that the human has the potential to effect the outcome of God's order.

Fred Rosner, a Jewish theologian, presents another perspective. We can judge the results of gene manipulation because it is no different than other organ transplants.\textsuperscript{123} Nelson also argues that any "authenticated cure" for a genetic disease cannot be a bad thing, noting that it will take several years or decades to determine the results of germ-line therapy. He is positive that this will be accomplished safely and with a realistic goal.\textsuperscript{124} In the meantime, Rabbi Seymour Siegel anticipates that advances in gene therapy will indirectly reduce the number of abortions. There is the possibility of improving fetal treatment for hereditary diseases to alleviate suffering.\textsuperscript{125}

Contrary to these arguments, Robert A. Brungs, S.J. advocates the belief that through gene therapy we are

\textsuperscript{121} Gustafson, "Where Theologians and geneticists Meet," 10.

\textsuperscript{122} Nelson, \textit{Life as Liberty, Life as Trust}, 70.

\textsuperscript{123} Perlin, "Jewish Bioethics and Medical Genetics," 339.

\textsuperscript{124} Gustafson, "Where Theologians and Geneticists Meet," 80.

attempting to make better people, the focus of the second of Nelson's categories mentioned earlier. He holds that since we are created in the image of God and Christ, we should not attempt alterations with gene manipulation, implying that humans are do not have the freedom to alter God's order.\textsuperscript{126} If humans and God are bound in a creation contract as equal partners with equal amounts of responsibility then not completing alterations would appear to be a breaking of this relationship.

A question that arises from the notion of co-responsibility is where will Judeo-Christians derive their sense of responsibility? Gustafson clearly states that humans have a blurred vision of rationality, assuming that our ways of knowing are the only ones. He also makes it clear that we misplace our values, making us insensitive to others.\textsuperscript{127} However much at fault humans are, there is still the potential to enlarge our vision, to understand the place of humans in the universe and to become accountable to the "well being of various "wholes" of which we are parts."\textsuperscript{128}

Sanctity of Life

Charles Curran points out that humanness involves more than science and technology allow, as they revolve within a limited sphere. "At times there are important human values involved which should not be sacrificed for the good of any science."\textsuperscript{129} Like theology and secular philosophy other disciplines have long held respect for the sanctity of life. This is defined in this thesis as life that is sacred.


\textsuperscript{127}Gustafson, \textit{Ethics From a Theocentric Perspective Volume One}.

\textsuperscript{128}ibid, 317.

\textsuperscript{129}ibid, 127.
Although there are varying interpretations of this principle, there is a common understanding, as Daniel Callahan suggests, that human life ought to be respected, while we pay close attention to the care of the weak and helpless.\footnote{Daniel Callahan, "The Sanctity of Life," \textit{Updating Life and Death} edited by Ronald Cutler (Boston: Beacon Press, 1969), 220.}

It is trusted that the sanctity of life is the thread combining all humanity and offers a foundational purpose of respecting human life based on its sacredness.\footnote{Callahan, "The Sanctity of Life."} The sanctity of life could be described as including the following: promoting the survival of the human species, aiding in making choices about the kind and number of human beings judged desirable, the right to bodily life, valuing personal identity which is violated when the body is involuntarily controlled by someone other than the one to whom it belongs.\footnote{This description was elicited from Callahan's "The Sanctity of Life."} Beauchamp and Childress indicate three fundamental points of agreement on the definition of the sanctity of human life:

1. Human Life is precious, even mysterious, and is worthy of respect and protection. Human worth is not determined merely by subjective or utilitarian concerns.

2. Human life may not be taken without adequate justification and human nature may not be radically changed.

3. The sanctity of life principle (or an equivalent principle) is basic to our society and its rejection would endanger all human life.\footnote{Tom L. Beauchamp and James F. Childress, \textit{Principles of Biomedical Ethics} (New York: Oxford University Press, 1989).}

How might a Judeo-Christian community establish the notion of the sanctity of life? \textit{Imago Dei} is the foundation for a Judeo-Christian perspective on life's sacred status. "As body and soul are united in a human, it is believed that
humanness bears the unique stamp of God's image, which determines the nature, value and meaning of life.\textsuperscript{134} Conrad G. Brunk questions this implying that the sanctity of a person in God's image differs from the sanctity of biological life.\textsuperscript{135} This is based on the absence of biblical authority.

I would refute this by arguing that the writers of the bible could not have had warrants for the sanctity of biological life, as we know it today, because they did not have the knowledge of biology that we now have. However, they could still appreciate physical life and consider it distinct from the spiritual. However, I agree with Nelson's statement because in the initial creation story in \textit{Genesis} human beings are created to God's specifications. There appears to be no distinction between the biological and spiritual. I believe that human sacredness includes both the biological and the spiritual.

Further criticisms of the Judeo-Christian view of the sanctity of life are expressed by Daniel Callahan. He suggests that for theology the sanctity of life indicates that human dignity ought to be outside of human judgment. Callahan has also indicated that this leaves humans unable to make judgments about themselves.\textsuperscript{136} He states that it is an "utter abdication of human responsibility to passively place on God's shoulders the care and protection of human life."\textsuperscript{137} What does this imply for the Judeo-Christian


\textsuperscript{136}Ibid, 190.

\textsuperscript{137}Daniel Callahan, "The Sanctity of Life," 215.
community? Callahan indicates that respect for human dignity is in human hands. Humans must choose human rules and judgments for issues such as gene manipulation.\textsuperscript{138} Gustafson's view of human nature and the relationship with God that arises from his perspective corresponds with Callahan's position on the sanctity of life. The notion of co-responsibility shifts the burden partially from God's shoulder to ours. So from this theological point of view human dignity is in human hands. It is also in God's hands. The point is that in a co-creation/co-responsibility model humans have a certain responsibility for their actions.

J. Robert Nelson, a Protestant theologian, believes that to be religious or theological "ought to mean being utterly realistic about the conditions of life in human society, regarding every person or institution or technical process with neither illusion or despair."\textsuperscript{139} Because of this realist approach, Nelson argues that the first principle in dealing with genetic therapy should be to do no harm and if the results are questionable, we should proceed with caution.\textsuperscript{140} This position can be summed up with the notion of nonmaleficence (do no harm).

Richard McCormick, S.J., is concerned whether gene manipulation will "promote or undermine" the person. To be able to accomplish gene manipulation with integrity we must recognize that to "judge the moral character of many human actions, experience of its impact on persons is essential."\textsuperscript{141} In other words we will never know the results until we try it! He says to determine the usefulness of

\begin{footnotes}
\item[138]\textit{Ibid.}, 215.
\item[139]\textit{Ibid.}, 77.
\item[140]\textit{Ibid.}
\end{footnotes}
gene manipulation we have to ask whether it will undermine human integrity.\textsuperscript{142} McCormick suggests that life is sacred because of the value God puts on it.\textsuperscript{143} This could be construed as absolute value but examining it through the lenses of co-creation/co-responsibility I would argue that the belief in \textit{imago Dei} may be the source of valuing human life but humans can also put value upon life.

Can humans and God both promote the sanctity of human life? In the previous section we discovered that human dignity and the sanctity of life can be promoted by both God and humans. Co-creation entails humans working with God to create. James F. Childress indicates that for Christians the ultimate reason for human dignity lies beyond utility and performance. For the Christian dignity lies in \textit{agape}. It has been suggested that \textit{agape}, and not the sanctity of life, is the basic value that the sacredness of life is based on.\textsuperscript{144} It ought to be indicated that the two can work in conjunction in an ethic for gene manipulation.

For a Judeo-Christian community this is a furthering of the relationship with God. The covenant is now expressed amongst humans, as well as, with God. This furthering of the covenant is expressed through \textit{agape}. Gustafson touches on this when he develops his notion of the natural human. Humans are both dependent and interdependent. Dependent because we are finite and interdependent because of our interaction with the rest of the world.

As well, Gustafson develops the idea of expanding the human vision, essentially embracing our place in the universe as we evolve and discover. Through the Judeo-Christian understanding of \textit{agape} the welfare of the human

\textsuperscript{142}ibid, 267.
\textsuperscript{143}ibid, 269.
\textsuperscript{144}John Rogers, \textit{Medical Ethics, Human Choices}. 
species ought to be highlighted. By reaching out to other communities God's love will be projected throughout the world.

Does belief in the sanctity of life affect gene manipulations? In a practical sense the sanctity of life offers a foundation from which to work when interpreting gene manipulations. In the Judeo-Christian tradition it is based on the belief in the creation in God's image. Furthermore, it is a principle that crosses disciplinary boundaries; philosophy and science can relate to the notion of the sanctity of life, making possible a broader acceptance of life's sacredness, regardless of their philosophical/theological underpinnings. The concept of the sanctity of life has an effect on gene manipulations because if human life is regarded by all to be sacred then we will ensure that gene manipulations do not erode our sacred status. In other words, if there is a general consideration that human life is sacred then we will see to it that gene manipulations are used to promote our sacred status. This can be accomplished through medical treatments that are not intended, for example, to eliminate genes from the human genome.

With the sanctity of life established as a basis from which to proceed it may be important to examine how the sanctity of life can be used, in a practical sense, to interpret issues. This will result from a discussion of moral and human rights which will arise from a theological examination of how humans make value judgments.

From Anthropology to Rights

This section investigates how people can make value judgments and focuses on the views of James Gustafson. He indicates that value judgments are based on imago Dei, the ability to make choices, and alter God's order.
Richard McCormick, and others, have closely linked the sanctity of life with the quality of life indicating that they need not be separate things and that they can be used together. In the Judeo-Christian context the sanctity of life is based on imago Dei while the quality of life relies on the qualitative judgments of humans. These qualitative judgments are based on values. This implies the question what do humans value? To reach a conclusion regarding this question would be quite difficult considering that each individual, each community and each institution will have a different set of values. A further attempt to comprehend how humans value may help us to understand why particular things, i.e. the sanctity of life, are valued.

James M. Gustafson indicates that humans have the ability to "recognize conflicting desires and valuations, and consider in the light of many other things, including our moral and religious beliefs, which values we ought properly to pursue." In Gustafson's anthropology our finite condition causes us to misplace our sense of valuation, turning it towards the individual. Thus, from Gustafson's point of view, our moral choices would be centered on ourselves rather than on the larger world or community. Gustafson suggests that we can counter this by enlarging our vision; situating humans in the universe, ordering our values according to God and essentially doing for God rather than having God do for us.

Gustafson states that the "human task is to decide what is the morally best possible course of events and state of affairs." To accomplish this he suggests that we consider

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146 Gustafson, Ethics From a Theocentric Perspective Volume One, 286.

147 Gustafson, Ethics from a Theocentric Perspective Volume Two, 302.
four points in discerning ethical issues: points to be considered, boundary conditions, presumptions and general rules (303). These four points are perceived under the assumption that all things in the universe are interdependent. Points to be considered involves the notion that wholes (institutions, groups, etc.) have set "patterns and processes" which are based on general rules. They determine the extent to which people and things "involved in the interdependence are of greater or lesser moral relevance" (304). Boundary conditions are subject to change in pursuit of desired ends, which Gustafson indicates determines how the boundaries are drawn. He uses the example of the just war which warrants killing (306). Biased presumptions are made that "cannot be overridden or violated without strong justification"(307). The fourth discernment indicates that general rules are based on values and these general rules can be altered in certain justifiable circumstances (310). However, in all cases the human must consider what ought to happen (310).

These discernments, as Gustafson refers to them, indicate ways that individuals and communities make their moral choices. He suggests that these judgments are not used to arrive at a rigorous course of moral action but instead make possible informed moral choices (315). Our best possible course of moral action will be varied. As participants in moral action, the Judeo-Christian community ought to relate their choices to their relationship with God. For Gustafson this is achieved by paying close attention to

particular relationships and events, the patterns and processes of interdependence of life in which we are participants [and the notion that] we are agents who can judge what ought to be valued and how, what principles ought to guide conduct, what ends to be sought (319).

It has been demonstrated that various theologians have differing views on the relationship between God and humans,
such as self-creation, stewardship or co-creation. In addition, we have demonstrated the views of James Gustafson on how we come to make value judgments. His perspective illustrates three things in regards to ethical decision making; 1. how humans take an active role in making these moral choices; 2. ethical decision making in relation to a Judeo-Christian belief in God is be based on imago Dei; and 3. humans are created in God's image and have the power to manipulate, alter and change the divine order set by their Creator.

To this point I have established that the concept of the sanctity of life is widely accepted in our culture. In addition, I have shown how some people justify their views of a value such as the sanctity of human life. Considering that there are several ways people can ground their values, i.e., religion and philosophy, we ought to consider how these values can be extended to rights.

Rights, Rights, Rights

Can a value such as the sanctity of life be translated into a moral right? David Hollenbach suggests that human sacredness is a characteristic of human beings rather than a value. For Hollenbach this is the fundamental human characteristic; "human persons have dignity". This is a slight change in language from sanctity to dignity. This change comes from the understanding that human persons have dignity and the reason they have dignity is because of the sanctity of life.

Hollenbach stresses the notion that human dignity is the foundation for human rights. He states that this dignity "is the source of all moral principles, not a moral principle itself. Particular human rights can therefore be

148David Hollenbach, Claims in Conflict (Toronto: Paulist Press, 1979), 89.
understood only when they are seen as rooted in this fundamental norm."\textsuperscript{149} Within this framework rights are "conditions for the realization of human worth in action" and refer to human freedom.\textsuperscript{150}

Jürgen Moltmann also stresses human dignity as a basis for human rights. He indicates that theology ought to try implementing the belief in \textit{imago Dei} as the foundation for human rights as set forth by the United Nations. Moltmann defines fundamental human rights as

those rights and duties which belong essentially to what it means to be truly human, because without their being fully acknowledged and exercised human beings cannot fulfill their original destiny of having been created in the image of God.\textsuperscript{151}

Like Hollenbach and Moltmann, George M. Soares-Prabhu, an Indian Jesuit, places the sanctity of life as a foundational point for human rights. He points out that the United Nations' Universal Declaration of Human Rights is flawed because it pulls together positive and negative rights. Soares-Prabhu considers negative rights to be civil and political rights ('freedom from') and positive rights are economic, social and cultural rights ('the right to'). These different rights are rooted in different concepts of human nature. Soares-Prabhu looks at the Bible as a basis for these rights. He elicits two things from grounding human rights in the Bible: 1. in both testaments the sanctity of life is affirmed; and 2. it demands a responsibility for the welfare of the powerless and the needy.\textsuperscript{152}

\textsuperscript{149}ibid, 90.

\textsuperscript{150}ibid, 91.


\textsuperscript{152}George M. Soares-Prabhu, "The Bible as Magna Carta of Movements for Liberation and Human Rights," \textit{The Bible as Cultural Heritage} (Maryknoll: Orbis Books, 1995), 90.
Hollenbach's interpretation of *Pacem in Terris* centers rights on human dignity. *Pacem in Terris* is the most "complete and systematic list of human rights in the Catholic tradition."\(^{153}\) Hollenbach claims that it has a much stronger foundation than the United Nation's list of human rights due to political compromise.\(^{154}\) The rights he derives from *Pacem in Terris* are: bodily rights, political rights, rights of movement, associational rights, economic rights, sexual and familial rights, religious rights and communication rights. In a broad sense all of these rights could have a place in a discussion of gene manipulation.

**Justice**

At this point an investigation of concepts of justice will be useful. Josef Pieper indicates that justice comes after rights: "right comes before justice."\(^{155}\) If rights are "claims to those things which are due individuals"\(^{156}\) and if justice comes after rights in this equation, then what is the role of justice? Unlike rights, justice bounds people by their duty towards each other (144). Hollenbach suggests that while rights follow a particular order in relation to each other, justice distinguishes this order.

Hollenbach discusses three types of justice; commutative, distributive and social justice (145). Commutative justice is defined as binding "individual to individual in the sphere of private transactions" (145). Distributive justice divides rights claims so that they are inclusive of goods that are social. Social justice orders

\(^{153}\)Hollenbach, *Claims in Conflict*, 66.

\(^{154}\)ibid.


\(^{156}\)Hollenbach, *Claims in Conflict*, 144.
rights through governments and legislation. One could say that justice begins with the individual relationships within communities, then the community deals with justice in a broader sense, dividing rights amongst members of the communities, finally governments legislate so that these claims can be met.

Observing that justice is based on individual relationships one can conclude that there is a sense of duty amongst individuals. This duty towards other people in our communities is evident in the Judeo-Christian notion of agape. However, there ought to be a distinction made between agape and justice. Josef Pieper indicates that justice creates a distinction of parties and acknowledges "where one cannot love."\textsuperscript{157} Doing justice is an external act with social consequence.\textsuperscript{158} For example, I believe that justice is served when people care for their children that have severe genetic abnormalities. This is more just than aborting the child because the burden of their life will be too great. Parents who face the social consequences of having the responsibility of a 'defective' child are doing justice by giving that child a life. Through doing this duty they create love.

Humans have a responsibility or duty to ensure their "neighbors" are afforded basic liberties. However, if humans disregard their responsibility in their interdependent relationship, justice cannot be present. If there is no sense of basic justice in terms of being responsible towards other human beings how can we arrive at distributive or social justice?

According to Judeo-Christian theology the relationship between God and humans is based on \textit{imago Dei}. From this

\textsuperscript{157}Josef Pieper, \textit{The Four Cardinal Virtues}, 54.

\textsuperscript{158}ibid, 64.
foundation we have determined that humans take part in a co-creative relationship with God. This co-creative arrangement entails co-responsibility; God created humans and now humans have the ability (and the pending responsibility) to create. The basic principle of this power and responsibility is the sanctity of life. Life's sanctity is based on human value. For the Judeo-Christian believer this value is found in faith in their God. Life's sanctity is the root of human dignity which forms the foundation for human rights. These rights are validated by justice which is based on individual relationships within a community. For a Judeo-Christian believer the individual relationship can be based on agape. In the context of the theology and anthropology that I present, "neighborly love" is defined as responsibility for the interactive relationships with our communities and within the universe. Justice, however, goes beyond agape, indicating that we cannot always "love." We have a duty to ensure the human dignity of all human beings. If this responsibility is carried out further forms of justice (distributive and social) can be put into action.

The material in this chapter presents us with a basis for interpreting the issues of gene manipulation. Through surveying views on gene manipulation from selected religious traditions and theologians we are able to derive various themes and principles. The major themes that arise are imago Dei, co-creation/co-responsibility, the sanctity of life and justice. Three indications arise from these principles: 1. because we are created in God's image human life is sacred; 2. we have the ability to alter God's order, including the human genome; and 3. with this ability to alter God's order we have a duty to ensure that human life remains sacred.
Chapter Three: Interpretation of Ethical Issues

The third chapter will interpret the ethical issues surrounding gene manipulation. I will base this interpretation on the principles identified in Chapter Two: *imago Dei*, the sanctity of human life, co-creation/co-responsibility and justice. This chapter is intended to focus on the issues that are most common in the discourse on gene manipulations and provide a forum for my theological response. The following is a list of the issues to be discussed: 1. screening; 2. enhancement; 3. eugenics; 4. discrimination; 5. just distribution and resource allocation; 6. privacy and confidentiality; and 7. patenting and genetic piracy.\(^{159}\)

In previous chapters questions regarding the issue of gene manipulation were raised: Can we value and accept people who have debilitating genetic diseases? What are our concepts of human dignity and worth and the value of the physically and mentally challenged? What warrants do we have to eliminate a disease from the genetic make-up because it is deemed abnormal? If the technologies are available, will they be made available to all of humankind, or only to those wealthy enough to purchase them? How feasible are some of these types of manipulation? In principle are they any different than existing procedures? Will we be faced with the possibility for misuse of genetic information? In order to cure one's genetic disorder, one's genetic information will become available. What does this mean to the idea of doctor-patient relations? Will the genetic

\(^{159}\) Ted Peters, "Why genes and theology?", *Dialog* 33, no.1 (1994). Peters indicates issues that are foreseen as ethical struggles for the future. These issues include genetic discrimination, abortion, "the perfect child syndrome," patenting and eugenics. These issues arise in much of the literature concerning gene manipulations. In Chapter One we pointed out several issues, some of which overlap with those suggested by Peters, and the ones we are discussing in the present chapter.
information be divulged to outside sources? What if we find, through prenatal testing that our child will develop a debilitating disease at a particular age or through other diagnostic tests that we will develop cancer at age 30, 40, or 50? With these questions in mind I will enter the theological discourse that exists concerning gene manipulation.

1. Genetic Screening: positive eugenics?

In this section I will enter the theological discussion that exists concerning genetic screening. I will also discuss subsequent issues that may arise in relation to genetic screening. These issues include: what it means to be human; suffering; reproductive choices; the long term consequences of these choices; and, our responsibility to future generations. In discussing and responding to this debate I think it is important to keep in mind that many of the theologians I have surveyed hold the view that the techniques used in screening are closely linked to positive eugenics. Screening will make 'positive eugenics' easier than it is presently.\textsuperscript{161}

The framework for this debate is set by various theologians who discuss screening by presenting general criteria for its permissibility. The main criterion is that screening is permissible for predictive health care as long as it avoids discrimination.\textsuperscript{162} Ronald Cole-Turner suggests that the occurrence of screening will increase over time.

\textsuperscript{160} These questions are taken from Chapter One of this thesis.

\textsuperscript{161} I refer to positive eugenics as selective breeding. This is something that is already done to a certain degree. For example, parents can choose not to have a child if there is a possibility of passing an abnormal genetic trait to the child. Genetic screening would make it much easier to make this type of decision because more genetic information would be available through diagnostics tests.

\textsuperscript{162} Nelson, \textit{On the New Frontiers of Genetics and Religion}, 197.
He says that an interpretation of the results of screening will result from a "broader cultural and religious framework" not from science.\textsuperscript{163} Scientists are going to create diagnostic tests and other screening techniques while disciplines like theology, sociology and philosophy are likely to evaluate what science has offered society. Genetic screening has crucial implications for people concerned with reproductive decision making and in other areas including insurance and employment.\textsuperscript{164}

**Humanness**

Humanness is an important aspect of this discussion because with genetic screening situations may arise where there will be a question of whether the screened, based on their genetic make-up, will be human or not. What is humanness? This question arises as a result of pondering why we would not want a child with a genetic defect. Joseph Fletcher presents fifteen positive and five negative criteria for being human.\textsuperscript{165} None of these criteria indicate that a person has to be "genetically correct" to be human, although one's genetic make-up could have a potential impact on some of these criteria, i.e., if a gene or genes caused a person to not fulfill Fletcher's requirements for humanness.

\textsuperscript{163}Cole-Turner, *The New Genesis*, 47.

\textsuperscript{164}The issues surrounding employment and insurance will be discussed later in the section on discrimination.

The doctrine of *imago Dei* is how Jews and Christians situate themselves as humans. Rabbi Ira S. Youdovin states that

our tradition affirms that humankind was created in the image of God...and while that in no way precludes tampering with a human being's DNA---if tampering enhances human life---it surely does preclude tampering with a human being's basic humanity.\(^{166}\)

In agreement with Youdovin, I have to say that humanness does include our genetic make-up. However, manipulating our genes does not change our humanness. Our genes help to make us human. The doctrine of *imago Dei* indicates that creation is in God's image and that human life is sacred. However, it gives no indication that gene manipulation will alter our humanness or sacred status. As co-creators, I would argue that using gene manipulation could be a way to maintain our sacred status as humans. It is a dynamic and creative way to change God's order. However, this does not mean that we cease to be human beings. Our genetic code will still consist of the same DNA make-up. If we somehow added to or took away from the DNA structure that creates our genes, then we may be altering humanness. However, I do not believe that there is any evidence to prove that loss of a gene would make a person any less human. Gene manipulation simply proposes to alter the genes, not what they are made from. Given this I would argue that through gene manipulation human beings can fulfill the role of co-creator and not threaten the sanctity of life.

**The Question of Suffering**

The question of suffering evokes various responses. Some religious leaders have responded by saying that suffering is a part of life and that "if there exists a gene

for Down's Syndrome [or other genetic disorders], then God may have wanted that; there may be a reason for it being there."\textsuperscript{167}

A second response to the question of suffering as a natural part of human life is based on perfectionism. One religious leader stated that "there's a certain wanting to get rid of all suffering."\textsuperscript{168} This response appears to be parallel with the idea of the quest for Utopia in the sense that it would be impossible to do. Creating a perfect genome is virtually impossible scientifically if one considers genetic mutations and the amount of time that evolution takes. We ought to accept, as Charles Curran points out, that we will not reach Utopia.\textsuperscript{169} We are not perfect creatures, nor are we creators of perfection.

Aside from our imperfection, ridding the entire human genome of particular deleterious genes would be an enormous task. This is not likely to occur. However, if this were accomplished there would be serious implications for the human species, as David Suzuki has suggested:

\begin{quote}
In evolution's grand scheme, genes - singly or in combinations - can be rendered instantly obsolete by a quick shift in competition, climate or some other unpredictable factor. Yet these same genes might just as quickly prove useful to survival in another time or place. This means that systematically culling genes that might appear to be useless - for domestication or any other purpose - is not simply a form of hygienic housecleaning. It can also be a blind destruction of the potential options in a species' evolutionary future.\textsuperscript{170}
\end{quote}

I think Suzuki is talking about genetic evolution that is only partly related to human involvement. I would argue, in

\begin{flushright}


\textsuperscript{169}Curran, \textit{Issues in Sexual and Medical Ethics}, 124.

\textsuperscript{170}Suzuki and Knudtson, \textit{Genethics}, 287.
\end{flushright}
a general sense, that human beings are not responsible for all changes in the environment that cause suffering. We have to take responsibility for environmental changes caused by human beings; changes that have an impact on the genes and cause suffering such as pollution, or the Chernobyl nuclear disaster, but human beings cannot be held accountable for things they do not have a role in.

A third response to suffering is that increased knowledge of a particular disease would be helpful for the parent of the child with the defects. This would help to "prepare the parents for the reception of the child, to work with the child."[^17] I interpret this to mean that the child would be loved into life. On the other hand the parents may decide to abort because they would have a better idea of what to expect from the child. They may decide that there would be too much suffering for themselves and the yet to be born child. I would argue that there is a duty to give birth to the child. The child may offer something that cannot be found in so-called normal children. I believe that through giving the child with a defect life and caring for it, even if it causes inconvenience for the parents or other children, love will result. This may be a case where agape is the result of fulfilling a duty. The parents may not want the perceived suffering but by having the child they may begin to have a different outlook on life. Initially they may not be able to love their child with a defect but the child may cause them to love. I would argue that this is justice at work because it creates love where there was none.

[^17]: ibid.
Reproductive Choices

How do we relieve the suffering caused by genetic disorders? I argue that there is a perception that we can only relieve the suffering through reproductive choices. From the theological discourse one could gather that the only options with genetic screening will be: 1. abortion; 2. in vitro fertilization; or, 3. a life with a genetic disability. I argue that there is a fourth option: loving a child into life. However, this raises serious concerns for parental care givers and society who would have to pay (economically). I would argue that we must take care to not reduce life to an economic commodity, for example, not having a child because of the economic cost. A fifth alternative will be gene manipulations. I would argue that gene manipulations would cost society just as much, financially as caring for a genetically defective child. Given this, our decisions are reduced to whether or not we want to raise children with genetic abnormalities.

Abortion

The theological dialogue surrounding genetic screening appears to revolve, in a general sense, around abortion. Abortion plays an important role in this debate because it is seen as the end result of a positive test for a genetic abnormality in a fetus. I do not intend to enter into the abortion debate, however, it will be discussed in brief to locate the arguments made by some theologians.

Pope John Paul II presents the view that screening for therapeutic reasons is legitimate, however, he indicates that screening is gravely opposed to the moral law when it is done with the thought of possibly inducing abortion depending upon the results: A diagnosis which shows the existence of a malformation or a hereditary illness must not be the equivalent of a death sentence.\textsuperscript{172}

\textsuperscript{172}Pope John Paul II, "Instruction on respect for human life in its
John Paul's instruction is similar to some Jewish responsa. Fred Rosner indicates that different rabbis will have different responses to affected fetuses. Rosner points out that some rabbis will suggest abortion in certain cases where the mother's physical or mental health is threatened. Other rabbis will not recommend an abortion.\footnote{Fred Rosner, "Jewish Medical Ethics," \textit{Journal of Clinical Ethics} 6, no. 3 (1995): 209.} He questions mass screening for diseases that cannot be controlled or cured. Jewish communities have had first hand experience with Tay-sachs disease. Rosner says:

\begin{quote}
[t]o eliminate Tay-sachs disease by selectively terminating affected pregnancies may not be acceptable in Judaism, although some rabbis do sanction such procedures. Although local support for Tay-sachs screening programs may be active, such support is usually limited to detecting the carrier state and does not include performing amniocentesis with the sole intention of aborting the fetus if it is found to have Tay-sachs.\footnote{ibid, 209.}
\end{quote}

Ronald Cole-Turner offers a solution to the problem that arises with abortion. He suggests that \textit{in vitro} fertilization would provide an alternative to abortion by screening the embryo to determine if the child would carry a genetic abnormality. The problem that arises is that there may be several aborted embryos.

\begin{quote}
We may regard it as redemptive intervention if a couple is screened, found at serious risk, and advised not to conceive a child. Couples who accept this as redemptive on their part will also see it as costly, inasmuch as they forego the opportunity for offspring.\footnote{Cole-Turner, \textit{The New Genesis}, 96.}
\end{quote}
Cole-Turner goes on to say that

in some cases, genetic diagnosis will lead to a course of therapy that will effectively treat the disease. In other cases, no therapy will be possible. The only medical intervention will be abortion. Some will regard this intervention as purely destructive or wholly without redemptive meaning because it can only end life. Others will regard it as having a redemptive intention: the avoidance of a life of chronic disease. Any redemptiveness in this act is mixed with unavoidable loss. 176

Evidently, the theological discourse on screening is largely concerned with abortion but as long as it is avoided, in most cases, screening is regarded as acceptable. Cole-Turner argues that this will ultimately be the decision of the parents and offers an alternative with *in vitro* fertilization. The only other alternative, it appears, would be a life of chronic illness.

**A Life with Congenital Defect**

Is giving a child with genetic illness life a valid reproductive option? The genetic defect may cause death at a very early age, so why not give the child life and love it while it is alive. This would avoid all the choices offered, with the exception of a life of chronic illness. Chronic illness may be a difficult thing to deal with. For some parents it will be the only reproductive alternative when faced with the challenges, as "normal" human beings, of dealing with a genetically abnormal child. The future may very well present us with increased genetic screening and diagnostic testing but we will still have to deal with the fact that chronic illness is unwanted and the question of can it be accepted? It may place a great deal of stress on the family of a genetically defective child but can we not ask what this child has to offer? Is the genetic "reject" without value?

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176ibid, 97.
A life with genetic disease is a valid reproductive choice for parents. There are two reasons for this conclusion. The first is that we are created in God's image and each person's life is sacred, genetic defect or not. Joseph Fletcher's criteria for being human includes persons with disabilities.\textsuperscript{177} The second reason is that \textit{agape} calls for unconditional love. I argue that if a genetic defect is too difficult to accept, then justice indicates that we have a duty to bring that person into life. The result of caring for this child will be the unconditional love that is depicted by \textit{agape}. In the case of genetic screening, abortion and reproductive technologies may be considered "cop-outs" for those who do not have the responsibility for what they create. I believe that if a child meets the criteria for being human that Fletcher proposes, then there is no reason to avoid giving this child life.

\textbf{Gene Manipulations}

As a fourth option for relieving the suffering of genetic disease we could consider somatic and germ-line manipulations.\textsuperscript{178} Somatic cell manipulations are widely accepted in society with the exception of a few religious groups.\textsuperscript{179} Elliot Perlin presents a Jewish viewpoint that also expresses the views of most other theologians on the issue of somatic cell manipulations; "in general it is permitted if it will ameliorate suffering and the risks are acceptable."\textsuperscript{180}

Germ-line manipulation, on the other hand, presents the

\textsuperscript{177}Fletcher, \textit{Humanhood: Essays in Biomedical Ethics}.

\textsuperscript{178}Somatic and germ-line manipulations were discussed in greater detail in Chapter One.

\textsuperscript{179}Nelson, \textit{On the New Frontiers of Genetics and Religion}, 197.

\textsuperscript{180}Perlin, "Jewish Bioethics and Medical Genetics," 338.
greatest concerns. Ronald Cole-Turner suggests that germ-line manipulation is "far too risky with current technology. During the next two or three decades, as the technology develops, it will be important to encourage ethical and theological analysis of germ-line therapy."\(^{181}\) The theological discourse concerning germ-line manipulation is summed up in J. Robert Nelson's "An Exercise in Correlation" where he indicates that there is a great deal of skepticism from scientists and "confirmed believers" alike. The scientific community sees it mainly as a "question of technical feasibility but debatable because of unknown risks and irreversibility of effects."\(^{182}\) According to Nelson's study confirmed believers hold "cautious to negative positions fortified by strong resistance to genetic manipulation for physical enhancement or eugenics."\(^{183}\) Others surveyed in his study appear to be "open to persuasion if the risk concern can be met."\(^{184}\)

Elliot Perlin presents the view that germ-line manipulation will deal with diseases that somatic manipulation cannot treat. He indicates that it would be great to have a treatment available which would relieve a family lineage of a disease such as Alzheimer's. However, he indicates that it would not be acceptable if it would lead to passing traits developed through enhancement manipulations. He argues that gene manipulations, including the germ-line variety, are acceptable if they "can be performed with acceptable risk and will benefit humankind."\(^{185}\)


\(^{183}\) ibid.

\(^{184}\) ibid.

\(^{185}\) Perlin, "Jewish Bioethics and Medical Genetics," 339.
Bruce Reichenbach and V. Elving Anderson offer a slightly different perspective because they do not draw a line between the "morality" of germ-line and somatic manipulations. They indicate that if one is permissible then they are both permissible. They offer three criteria for determining both: 1. Is it necessary? Is there another effective treatment available? 2. Is the procedure effective?; and 3. Is the procedure safe?186 The Medical Research Council of Canada, however, does not have the same perspective. They see germ-line manipulation as quite different from the somatic cell variety and deem it unjustified at this time because of the potential to alter the human gene pool and because of the few instances where both parents carry the recessive trait for a disease.187

We will still have to ask ourselves if these manipulations are right or wrong. If germ-line manipulations were viewed as being morally acceptable we could cease with the theological debate because they would be permissible. At the present time it can be justified that germ-line manipulations are not permissible. However, as knowledge of germ-line manipulations increases we will either have forgotten our present concerns, and they will suddenly appear as legitimate, or our fears will be maintained.

I believe that eventually society will proceed with germ-line manipulation, even if it is only available to the wealthy elite, to continue their "strong" genetic family lines. If, or when, we do proceed with germ-line manipulation we will be faced with further issues. When we


consider these issues we will be better able to decide if germ-line manipulations are legitimate. At this point I would argue that germ-line manipulation is feasible based on the notion that we are co-creators and have the ability to alter God's order. I think germ-line manipulation is acceptable but we must be willing to use it in a responsible manner. Although these manipulations are open to misuse we must not dismiss them based on the fear of misuse.

Long Term Consequences

What are the long-term consequences of gene manipulations? The long-term consequences of gene manipulation cannot be predicted but, as Richard McCormick suggests, we will never know the consequences until we try to attain them.\textsuperscript{188} Rather, the question is should we continue with these manipulations regardless of the long-term consequences?

One concern is that we will not be able to correct mistakes that may arise with germ-line manipulations. We will be able to change the germ-line and that will result in a seemingly long-term solution to the inherited genetic defect but what is to be done when the germ-line develops a new mutation that results in a new genetic defect? Joseph Fletcher presented the notion that if we make mistakes through our technology we should fix them with further technology.\textsuperscript{189}

Both McCormick and Fletcher present illuminating points. We have to attempt germ-line manipulation before we can actually make the mistakes and, as Fletcher points out, if we do make mistakes we will have the potential to create further technology to fix those mistakes. However, this is

\textsuperscript{188}McCormick, \textit{The Critical Calling}.

\textsuperscript{189}Fletcher, \textit{The Ethics of Genetic Control}.
not the core issue that germ-line manipulation presents in terms of its long term consequences. The main issue is whether or not it is right or wrong.

**Responsibility to Future Generations**

Do we have a responsibility to future generations? Are we responsible for their genetic health? If so, ought we proceed with germ-line manipulations? The concern arises for both the human species and individual families. What impact will germ-line manipulation have on the survival of the human species? What impact will it have on the maintenance of individual family lineages? At this point we do not know.

Eugenicists in the 1930s "claimed that we owe it to future generations to fix their genes!"190 Today we have to question how valid their claims were. Some theological views would argue against this. Paul Ramsey has suggested that God intends to kill us all in the end.191 If this is the case it will make little difference what our genome consists of. If we consider the many implications of passing genetic traits to future generations it appears obvious that we have a responsibility to these generations. Fred Rosner highlights the problems with passing the sickle cell trait to future generations. We not only rouse medical implications for people who are affected but ways that their lives are affected in a practical manner; such as loss of jobs or paying higher insurance premiums.192

Ronald Cole-Turner holds that "we are not responsible for the genes we inherit, nor should we feel guilty for what

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191 Ramsey, *Fabricated Man*.

192 Rosner, "Jewish Medical Ethics," 209.
we inherit." He goes on to say that "our genes carry the legacy of our evolution; and our personhood itself, including our capacities for consciousness, moral decision, and faith, arises from our genes as selected by evolution." If this is the case I would argue that there is a responsibility to pass our genetic traits, defective or not, to future generations based on the doctrine of *imago Dei*. I believe that because humans are created in God's image our genetic make-up is special. Human beings do have the capacity to alter God's order but why should I want to change what I have been allotted by God, given that my genetic make-up is sacred? Based on my understanding of the religious traditions and opinions that I have surveyed I would argue that we ought to accept the genome we have because it is sacred, regardless of whether manipulations are legitimate or not.

Bartha Knoppers offers a different forum for this discussion. She refers to "genetic heritage" as the "inherited characteristics as expressed in the outward appearance of an individual (the phenotype)." In terms of Knopper's definition of genetic heritage, and this appears to be the definition we are concerned with, do we have a duty to *discontinue* deleterious traits in our genetic heritage or family? Knoppers indicates that the right to procreate includes both the choice to procreate and the choice not to procreate. Choosing to procreate includes the freedom to "select or control the characteristics of offspring, such as to prevent harm to them." She goes on

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194 Ibid, 170.


196 Ibid, 56.
to say that respect for human dignity is "manifested in a respect for decisions that are as private and personal as the decision to bear a child, under what conditions and with whom."\textsuperscript{197} Deciding to procreate on the basis of the potential genetic make-up of the child is a personal decision that will be reflected by the individual family's world view.

We do have a responsibility for the genetic health of future generations. According to Knoppers we have a responsibility to pass whatever genetic traits to future generations that we, as individuals see fit.

The problem that arises is that everyone will have a different view of what is genetically fit. In the future we will have to determine what this means. Does genetic health mean that individual family lineages will be free from genetic aberrations?; or do these genetic abnormalities act in a way that allows those of us who have a "normal" phenotype to sustain life as we know it?

I would argue that we ought to be more concerned with the survival of the species than with the health of specific families because the wealthy are more likely to be able to afford to benefit from gene manipulations than the poor. Considering this, I think we have to look at the "big picture." In that picture human beings are a part of an interrelated system of processes and events. If we attempt to alter those processes and events, although we are quite capable of doing this, we may cause more harm than we anticipate by simply ridding a family of the challenge of having a genetic abnormality in their lineage.

\textsuperscript{197}ibid, 57.
2. Enhancement: The Perfect Child Syndrome

Gene enhancement manipulations are touted as having the potential to alter the outward appearance of an individual. This section focuses on whether our fears of enhancement are legitimate and whether we ought to seek "perfect" children or accept the children that are born. In addition, I will elicit some positive roles that may warrant the use of these enhancement manipulations.

Legitimate Fears?: A Look at the Slippery Slope

The various theological perspectives that arise in this conversation elicit two important points. The first is that there is a good deal of fear and disapproval towards genetic enhancement. The second, contradictory point, is that many potential parents would be quite willing to use enhancement for the benefit of their child's future.

Although W. French Anderson suggests that enhancement of the genome is a form of genetic therapy it is more widely considered the bottom of the slippery slope of germ-line manipulation. J. Robert Nelson indicates that there is a general disapproval of enhancement, although the arguments for it range from approval in situations of "pragmatic judgment" to "marginal cases such as dwarfism."\(^{199}\) Richard A. McCormick argues that enhancement is "not therapy in any traditional sense; nor is it scientifically feasible at present."\(^{199}\)

Some sources argue that enhancement of the germ-line is similar to giving one's children a fine education, a European vacation, or simply a better chance at achieving a better stake in life, according to our present societal


\(^{199}\) McCormick, *The Critical Calling*, 266.
Is our fear of enhancement legitimate? Rabbi Ira S. Youdovin, of New York City, indicates that our fears of genetic enhancement are quite legitimate. He suggests that there would be a strong demand for such procedures.

I've seen too many parents go "bonkers" when their four-year-old doesn't get into the absolutely best kindergarten, which diminishes his/her chances to get into the absolutely best college---which ruins the child's life even before it begins losing its baby teeth.

As suburban parent, I've seen too many parents berating their Little Leaguers for lacking athletic skills that might earn them a college scholarship.

But judging from the billions of dollars we spend each year giving music lessons to the tone deaf, ballet instruction to the clumsy, and art classes to kids who can't draw a straight line---I'm simply not prepared to guarantee that potential parents could resist the temptation of visiting their friendly neighborhood geneticist.

Moreover, as the iron logic of supply and demand would make this technology available to the affluent only, there would soon develop a permanent genetic underclass, unable to compete with those whose intelligence and other skills have been elevated by selective breeding.

Youdovin goes on to say that the slippery slope begins as a "perfectly rational, ethical and, indeed laudable [idea]---something like planting a healthy gene to spare an as-yet unborn child the agony of a short and painful life." This ideology brings us back to the arguments surrounding suffering; which we argued came down to reproductive choices.

Another Jewish perspective, from Rabbi Barry Freundal, indicates that "cross generational intervention for positive purposes...is permitted." This is based on the grounds that the Talmud "allows prenatal intervention for

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202 *ibid*, 25.

intellectual-ethical and even for aesthetic reasons." He is optimistic that manipulations to "solve a particular problem would seem to be appropriate in any area" although he says that "fundamental alteration of personality would seem to threaten destruction of the individual and would raise *Brave New World*-style fears." 

Our fears of enhancement are legitimate, if we focus on the negative aspects. If we consider that parents want their children to have the best possible conditions in their lives, as Youdovin seems to be suggesting, we ought to fear that gene enhancements will be widely accepted by those who can pay for them. It seems to me that enhancement manipulations will become legitimate as demand for them increases. I think they are a legitimate alternative to some of the present, however archaic, forms of enhancement mentioned in this section.

**Perfection or Acceptance?**

There is no question that enhancement manipulations will eventually be made available. Is it wise to make such choices for our children? Ted Peters indicates that through the use of enhancement technology an image of the "perfect child" will be created. He indicates that those parents who do not choose to use enhancement (or those that cannot afford it) may present the opportunity for discrimination of both themselves and their children. For Peters, the Christian response ought to be to love each person regardless of their genetic make-up while the secular version will be that "each person should be given full rights and opportunities regardless of his or her genes." 

\[204\] ibid.

\[205\] ibid.

\[206\] Peters, "Why Genes and Theology?," 3.
I am in full agreement with Peters, the WCC, the United Church of Canada and John Paul II, that each person ought to be loved and given full rights and opportunities regardless of their genetic make-up. This is implicit in the notion of *agape* that I presented earlier. However, what Peters suggests as the secular version of *agape*, corresponds to the principle of justice. It indicates that the Judeo-Christian tradition must go one step further than love. Justice acknowledges a duty to ensure that each person be given full rights and opportunities regardless of their genetic make-up. Justice covers the areas that love cannot.²⁰⁷

What enhancement can be reduced to is a choice for our children. The problem is that our choices may not reflect the way the child would choose to live their life. Consider the case of a child born addicted to cocaine, commonly known as "coke babies." The parents of these children make choices that reflect their disease and may greatly affect the child; drug addiction. Similarly, if a child's genome is manipulated so that the germ-line passes a particular trait, the child may be burdened by the trait. If a parent altered the germ-line to enhance the child with large muscles the child may, conversely, desire to become a ballet dancer. The hypertrophy of the muscles would hinder their graceful leaps.

When they become available what enhancements would parents choose for their children? Rabbi Youdovin and others suggest that parents may want to give their child a gene to be taller so they will play professional basketball or so they will develop large muscles, or enhance their general athletic ability. Others will want to increase the mental abilities of their children, or maybe make their child look pretty. The potential list of enhancements is as

²⁰⁷ See our discussion of Justice in Chapter Two.
long as the sequence of the entire human genome!

If a parent wants their child to have characteristics that they themselves do not possess I would question the honesty in their motive. The parents who choose to implement enhancement manipulation may have some personal insecurity that they wish to solve in their children. The child will develop the characteristics the parent desires but will the child not have its own desires and choices? The child may be limited in those choices because of the potential of these characteristics to hinder the child. The parent may have "good intentions," like giving the child a better life, however, parents have only so much influence in the development of their child. One may wish their child to be a doctor but surely enough the child becomes a professional wrestler. What good were the enhancements?

Positive Applications for Enhancement Manipulations

Are there positive applications for gene enhancement techniques? Rabbi Freundel and J. Robert Nelson both indicate that positive manipulations would be permissible in certain situations such as dwarfism. Presently there are treatments, such as growth hormones, for those considered dwarfs. Giving a dwarfed child the chance to grow taller, to be "normal," could be considered a type of enhancement. I would also compare enhancement to diabetics. Synthetic insulin has helped diabetics survive and pass their trait on to their offspring.

This list can be continued further. One instance is the use of anabolic steroids to stimulate athletic ability and physical appearance. Other instances arise with silicone breast implants and other cosmetic surgeries that are used to "enhance" our bodies. Furthermore, mind altering chemicals such as LSD are used to "enhance" the mind. These are not a result of genetic manipulations, as
we refer to them, but I would argue that they do the same things that some genetic enhancements intend to do. The question that arises is whether we want our children to use the present, however archaic, "enhancement" techniques or provide them with a potentially more healthy form that is built into them. Parents could at least provide their children with the potential to turn a gene on or off. This returns us to the argument that we have a responsibility towards the genetic health of future generations.

I think that enhancement manipulations are acceptable if they are performed for an individual but not if they are used to alter the germ-line based on the preconceived notions of a parent's view of the world. I think that the debate comes down to whether we can accept people for what they are or might be, regardless of their genetic make-up. I would argue, as Ted Peters does, that we should love our children for who they are, not what we want them to be.

Unfortunately our society is plagued with the very attitudes that Rabbi Youdovin so honestly depicts. I think that our fears of enhancement gene manipulations are legitimate but we must also consider that they may provide us with some positive applications. I believe that each human life is given and maintained for a purpose. Each life is special in its own way, whether a person is big, small, fast, slow, or even incapable of functioning in a way that the majority of people do. I think this is expressed through imago Dei and the sanctity of life. Societal norms, that may pressure people to try to be what they are not, may disagree with this. Those people who choose to buy into the societal norms relieve any responsibility that God has in their life. This places the responsibility of life solely in their own hands, to be dominated by the ever changing norms of society. When individuals can see the value of themselves and others for who and what they are, not what we perceive
they should be, then we can cease to be afraid of enhancement gene manipulations. Until this is achieved, I think that love will arise through a duty to be willing to accept people for who they are.

3. Fear and Loathing of Our Own Master Race: Eugenics

In this section I enter the dialogue surrounding eugenics. Can we expect that eugenics programs will evolve from the Human Genome Project? Within the theological debate eugenics is discussed, with close attention given to the example of Nazi Germany, as well as the sterilization programs in Canada and the United States. Rather than going into a detailed discussion of the theological positions on eugenics a summary of theological points of view on the subject would appear to indicate that eugenics is not condoned by any theologians that taking part in the dialogue. There is a great deal of fear that arises from the potential for it to "become a tool for totalitarians engaged in ethnic cleansing."206 Ted Peters suggests that eugenics is enhancement "writ large."209 Richard A. McCormick states that "contemporary scientists run from positive eugenics as if it were the plague."210 Furthermore, it has been suggested that

knowing about heredity has always been vulnerable to short-sighted, self serving, even blatantly cruel ends - often for what seems to be the noblest of motives. Knowing this, we must remain vigilant against future attempts to use genetics to reshape human heredity according to someone's illusory idea of human perfection.211

I would question whether the powers that be in our society

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206 Peters, "Why Genes and Theology?," 3.

209 ibid.


211 Suzuki and Knudtson, Genethics, 23.
tend to be vigilant or "short-sighted, self serving, even blatantly cruel." It would appear that we ought to be afraid, very afraid, considering the potential role of large corporations in the future of genetic research. Of course my theological perspective, like others I have surveyed, does not warrant eugenics. Unlike McCormick, Peters and others who conclude that eugenics will not occur, I am skeptical. Perhaps this skepticism comes from the great influence of pop-culture on my generation but there is a question of whether totalitarians are the only ones interested in ethnic cleansing (or at least genetic cleansing). I think this is evident with seemingly harmless screening programs. I believe that these programs plant the seed for stronger eugenics goals.

It was suggested that scientists are likely to avoid eugenics but this raises at least one question: did the scientists in Nazi Germany think they were doing anything "wrong" when taking part in the eugenics programs? What about the eugenics movements in Canada, the U.S. and England? There is always the potential to slide the slippery slope into eugenics. I would argue that the Human Genome Project will open the door for eugenics programs and once they are seated comfortably in the status quo we won't even blink an eye to them, much like legalized euthanasia in the Netherlands. I think that this slide may be activated by private corporations becoming involved on a large scale, either through patenting gene sequences or seemingly harmless diagnostics tests. Our only saving grace will be found in our laws.

\footnote{See McLaren, \textit{Our Own Master Race: Eugenics in Canada, 1885-1945}.}
4. Discrimination

Stigmatization as a result of genetic abnormality, as well as discrimination in employment and insurance, are the discussion topic for this section. Ted Peters indicates that as diagnostic testing becomes cheaper the likelihood of insurers and employers using the information will increase. Other sources suggest that this information "might encourage stigmatization of those with genetic abnormalities and their exclusion from normal community interactions." Two common examples used to express this notion are Tay-sachs disease and the sickle-cell trait. However, it could include any genetic abnormality that alters an individual's outward appearance or their behavior.

Stigmatization

It is important to recognize that we already experience stigmatization, or discrimination, and exclusion from social interaction based on genetic abnormalities. There is a long list of socially stigmatized conditions based on genetic abnormalities. These could include Down's Syndrome, deformed limbs, as well as common genetic traits passed on such as baldness, being tall and lanky or short and stout. To say that we will potentially stigmatize people with genetic disorders is to be oblivious to the fact that we already do this.

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213 Peters, "Why Genes and Theology?" 3.


Reichenbach and Anderson point out that we not only have to be concerned
with the possible stigmatization of others who have serious genetic defects; the potential discovery of our own genetic heritage also might affect how we understand ourselves. It is estimated that every person carries five to ten seriously defective genes. If this is the case, how will we deal with ourselves when we realize that we are not perfect, that every cell in our body is flawed in some way?  

In response to this it has to be said that nothing is perfect. To attain perfection is impossible. As I have mentioned, Utopia is unreachable. Rather than seeking genetic utopia, Christianity and Judaism both advocate genetic diversity, and this appears to be the basic issue. Rabbi Barry Freundal indicates that for Judaism this diversity of human beings is "assumed and accepted." He goes on to say that
in certain circumstances, such as encountering an individual of different racial appearance [or other appearances] after not having had such an experience for a while, a blessing is recited praising God for creating diverse types of people in his world.

Another point that Reichenbach and Anderson argue is that the stigmatization may cause anxiety in terms of reproductive decision making. As well, they indicate the potential for guilt in dealing with defective children. They [parents] may see a genetic defect in their child as an occasion to blame either themselves or their ancestors. In short, the revelation of our genetic fallibility can be as an occasion either for acceptance of the human condition of finitude or for guilt and self-incrimination.

These are legitimate choices but from my theological perspective it is more a matter of taking responsibility for individual reproductive choices than to accept human

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216 Reichenbach and Anderson, On Behalf of God, 199.


218 ibid.

219 ibid.
finitude or guilt. We are created in God's image and therefore have infinite value or sanctity. I believe that guilt and self-incrimination arise from not considering all the potential reproductive choices. I think that if we are aware of our genetic traits we can better make these reproductive choices, thus avoiding guilt and self-incrimination.

**Discrimination in Employment and Insurance**

Further implications of discrimination arise with employment and insurance. If the information from genetic diagnostics tests becomes available the opportunity for discrimination in both employment and insurance will arise. This is an area that theologians have not discussed a whole lot. Their basic conviction is to avoid discrimination at all costs.

Queen's University professor, Jerome E. Bickenbach, indicates that if the information is available it will be misused. He states that "discrimination based on genetic information, or misinformation, about an individual -- genotype discrimination -- is most closely related with discrimination on the basis of mental or physical disability (or perception thereof)." He also makes it clear that this type of information will likely result in discrimination in relation to insurance, employment and access to health care resources. Bickenbach indicates that for law the best example of genetic discrimination is in the workplace and argues that genetic disorders are the same as disabilities. With Bickenbach's insight in mind I

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221 *ibid.*

222 *All quotes in this note are from the aforementioned article by*
would conclude that although we will not avoid discrimination there are legal safeguards in place that will empower those who may face genetic discrimination. Our duty to other human beings can be asserted through our laws. We have a responsibility to ensure that these laws are upheld when the situation of genetic discrimination arises and, as Bickenbach points out, it will arise.

Insurance presents other challenges to individuals that may have genetic abnormalities. There is fear that insurers will make use of diagnostics tests to exclude people from insurance or charge higher premiums. Genetic tests that have the potential to predict with a great degree of precision would be marketable in the insurance industry.

Jerome E. Bickenbach: In the U.S. "preemployment medical examination or inquiries other than those directly related to the ability to perform job-related functions" are prohibited. In order for genetic information to determine if a person in "disabled" the individual would have to be "symptomatic of the genetic disease or condition." In this context "disability" is defined as a "physical or mental impairment that substantially limits one or more of the major life activities of [an individual], a record of such an impairment, or being regarded as having such an impairment." In the context of genetics, "impairment" is referred to as "physiological disorder or condition" or an "anatomical loss affecting one or more of several body systems." Due to these definitions people with recessive traits are considered impaired because they can pass the gene on to their offspring, indicating a defective reproductive system. Discrimination against asymptomatic carriers of defective genes is based on "the belief either that the individual may in the future become disabled from the disease, or else may have children who will suffer from the disease." If an employer refuses to hire an individual on these grounds "the employer is obviously treating the person as if they were disabled -- disabled, so to speak, by the causal link to some future disabled condition. This means that the individual is regarded as disabled."

In Canada the protection against discrimination of disability is not as broad as it is in the U.S. We rely on human rights codes and the Charter of Rights and Freedoms. Bickenbach indicates that the applicability of human rights codes relies on the question of whether genotype discrimination is a form of discrimination on the basis of disability. He argues that it does because there are cases in law where asymptomatic conditions are considered disabilities. As well, our human rights codes describe handicaps and disabilities as both "existing impairments, a history of an impairment and a perceived impairment."

The last argument he gives is that "at the Federal level authority for the proposition that an increased risk of developing a disease is a disability, even though the person who is affected does not have that, or any other disease."
J.A. Lowden, Vice President and Chief Medical Director of Crown Life Insurance Company, indicates that predictive tests are only as good as the information they predict. Pre-symptomatic testing is useful to a degree while predisposing tests are said to have "little predictive value at this time." 223

With science progressing at such an alarming rate it is likely that this type of testing will become available in the next few years. 224 When it does become available insurers will be challenged with the opportunity to increase insurance premiums based on improved diagnostic tests. One case where this is happening is with colon cancer. There have been five genes identified that cause inherited forms of colon cancer. This type of information would be very useful to insurers.

As the Vice President of Crown Life Insurance, Lowden indicates that this information could be used in a positive manner. His position is that if an individual is aware of their potential to develop a disease like colon or breast cancer they will be able to take preventative measures. The

223 J.A. Lowden, "Genetic Testing and Screening in Insurance Underwriting," Symposium on Genetics and the Law [Tab 7] (Toronto: Osgoode Hall, 1995). Presymptomatic diagnostic tests determine whether if an individual will get a disease before any symptoms appear. Predisposition diagnostic tests reveal if a person is predisposed to a genetic ailment but they may not develop the disease.

224 Thomas J. Bigby of Visible Genetics, a Toronto based DNA diagnostics company, made it quite clear at the Symposium on Genetics and the Law that diagnostics companies are interested only in making profit. Single gene defects do not present a great enough market for profit so, like insurance companies, they are interested in multifactorial diseases. Genetic diagnostics test manufacturers are concerned with multifactorial diseases such as heart disease and cancers that account for deaths of the population. Presently there is a limited amount of literature on the "predictive value of DNA tests for multifactorial heart disease and even if they were available and cheap they would be of limited use to the underwriter until these data are acquired." DNA tests are far too costly to warrant their use for insurance purposes. Great numbers of tests would be required, genetic counseling would have to be provided to the applicant, predictive values are unclear and the applicant may not want to know this information.
diagnostics will make the disease identifiable early on, making the disease potentially preventable and, in Lowden's eyes, making the individual insurable because of the decreased risk. He says that "if we wish to protect the public from misuse of the new technologies let us concentrate on protecting privacy rather than developing inhibitory legislation in the unknown." Genetic diagnostic tests offer insurers information that they already have at their disposal. They can make predictions for the diseases that they are most concerned with a certain degree of accuracy. Although Lowden's vision promotes the best

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225 J.A. Lowden, "Genetic Screening and Testing in Insurance Underwriting."

226 Legislation covering DNA tests is non-existent in Canada and insurers are free to use the tests if they wish. In the U.S. several states, including Arizona, Wisconsin, Ohio, California, Colorado, Georgia, New Hampshire and Massachusetts, have created legislation to "protect applicants from unfair discrimination based on their genetic makeup." Lowden does not view this type of legislation in high regard. He thinks the controls should surround privacy. He indicates that the focus should be on protecting confidential information. Agent access to records, which sometimes goes beyond "corporate confidentiality practices and rules," should be limited. He suggests that APRs ought to be formal rather than photocopies. The predictive value of tests ought to be based on "solid scientific documentation to support a claim the abnormal results represent a true risk." And, finally, communication of decision regarding the tests ought to be explained by someone who knows what they are talking about. "If you are told your p53 gene is abnormal, what does that mean?" Can anyone, in fact, provide an informative answer to this question?

227 Aside from statistics, insurers use application form information, an attending physician's report (APR), medical examinations, Medical Information Bureau (MIB) codes and laboratory tests to determine an individual's insurability. Application forms screen primarily for premature death in the family. This is used a predictive measure in determining life expectancy. It is also widely considered a genetic test. The APR is sought from the family doctor and lists serious complaints, diagnoses and treatments and includes copies of relevant lab reports. This may include genetic information. Lowden points out that this information is often photocopied and sent to the insurer. He says that this "expeditious approach infringes on the confidential nature of the physician-patient relationship." On top of this Lowden indicates that "agents and brokers collect APRs and maintain copies of their clients' medical records in their files, a practice which breaches most medical codes of ethics."

Further medical examinations have been eliminated due to high costs but health care professionals take blood pressure and tests, health history, urine samples, and the weight of the client. Blood pressure and body type are the two most useful tools in predicting risk
interests of the public, other insurance companies may present different views. There will always be potential for misuse.

I think that we have to be concerned with the time when the diagnostics tests become available to insurance companies. These types of diagnostics tests are not useful to the insurers at the present time but they will be. When they are useful and practical they will be made use of. The

for the insurance underwriter.

MIB codes help to eliminate fraud. These codes are closely regulated. Medical conditions are reported to the bureau in numerical codes. These codes offer a broad description of maladies. This database is available to all member insurance companies but they must reconfirm this information. Many diseases which are "clearly genetic or have a significant genetic component" are not identified as genetic diseases. Cystic Fibrosis and hemophilia are two such diseases.

Lab tests can include genetic information and generally come from two sources. The APR will include any genetic information and clarify the past health of the applicant. Lowden points out that any genetic tests in the APR are interpreted by geneticists. This is important because the physician and the insurance company's medical director may not fully understand this information.

The insurer will also conduct its own lab tests. These include stress tests, blood and urine samples and chest x-rays. The request form for these tests is always signed by the applicant and samples are identified by the applicant's signature. These tests are often viewed as absolute by "non-lab" people. The implications of this are vast. He says "if DNA testing is used before the predictive value of specific tests has been demonstrated, many errors could be made in risk assessment." The problem is furthered by commercial labs that may claim that a "new test will solve the underwriter's worries. The underwriter may believe the claims and begin to rate on the basis of a test which in reality has little predictive value."

Should these tests be used to determine whether an individual receives insurance? Lowden points out that this depends on the definition. The insurance aspect of the Ethical, Legal and Social Implications of the Human Genome Initiative (ELSI) offers a broad definition of genetic tests that includes: "Family history and pedigree analysis, physical examination, laboratory tests, including: DNA testing, chromosome analysis, gene product analysis and metabolite analysis."

This definition includes many of the techniques already used in insurance underwriting. As Lowden points out, the insurer does not care how it gets its information, the result is what is important. Although family history is regarded as less factual than diagnostics tests, it "may be highly significant in risk assessment." Furthermore, Lowden presents the status of our information about mutations that produce disease. Presently they are focused on single gene defects like Cystic Fibrosis and Muscular Dystrophy. However, insurers are not concerned with these diseases.
real issue that arises from concerns about insurance is economic. The cost of testing, when it is available, may cause insurance premiums to rise. As well, if an individual is at risk they may have to pay higher premiums or be rejected but this is already the case. If there is a case of discrimination, the laws we pointed out can be made use of.

I agree with Lowden when he points out that the real issue is protecting the privacy and confidentiality of an individual's genetic information. I think that the core issue of privacy and confidentiality is discrimination and if this is to be avoided we will have to take certain responsibilities in our reproductive choices.

5. Just Distribution and Resource Allocation

This section will attempt to situate just distribution and resource allocation in Canada. In addition, we will try to answer the following two questions: can we distribute gene manipulations in a just manner? and; with our present financial situation, can we legitimately embark on a quest to fund these manipulations?

Setting the Scene

Jerome E. Bickenbach suggests that the "accumulation of genetic information, at first voluntarily provided, but eventually mandatory, will be viewed as an essential planning tool for strategic planning and resource allocative

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226 In their book, *Principles of Biomedical Ethics*, Tom Beauchamp and James Childress define the norms of just distribution as: 1. strict equality—to each an equal share, 2. according to need, 3. according to effort, 4. according to social contribution, and 5. according to merit. Each of these norms of just distribution offers a different notion of how to distribute resources. The authors of *Bioethics in Canada*, discuss the same categories with philosophical theories of distributive justice; utilitarianism, libertarianism, socialism and the merit standard. In Canada the utilitarianism has played a dominant role in distributive justice.
decisions." With this in mind, "will advances in genetic medicine add one more brick in the wall that separates rich from poor?" A recent survey of religious leaders' attitudes towards gene manipulations implied that "fair and equal access to this technology would need to be assured, and that discrimination in access would need to be avoided." However, some of the religious leaders surveyed were "skeptical that this [genetic technology] will be distributed to people in an equal way, it will be the privileged people who can take advantage of this, and that's my greatest fear." The fear that gene manipulations will be limited to a select few, i.e., wealthy white males, is something that ought to be of concern to Judeo-Christian and secular communities alike.

From my theological perspective I would argue that we have a duty to provide access to all in need. The scientists and doctors formulating gene manipulations may intend to aid those who are sick, weak and poor but like so many other things in our world, they are created by the "affluent, the powerful, those on top." Our economically based society neglects those that cannot pay.

Gustavo Gutiérrez's notion of those on the "underside" of society holds true, not only in Latin America, but in North America as well. Gutiérrez indicates that human rights to food, clothing, employment, shelter, education and, for our purposes, health care are "usually defined as

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229 Bickenbach, "The Human Genome Project and Health Law: Genetic Discrimination."

230 Peters, "Why genes and Theology?," 3.


232 Ibid.

privileges, available to those who can pay for them" in North America.\textsuperscript{234} However, human rights based on human dignity, the sanctity of life and \textit{imago Dei} result in a justice that goes farther than being able to purchase one's "rights" as a human being. We have a duty to the sick, weak and poor. There is no doubt that we can fulfill our duty to the sick but gene manipulations may not fulfill our duty to the weak and the poor. Gene manipulations intend to relieve our society of "genetic weakness" and those who cannot pay will remain poor simply because they do not have the economic means to attain the services offered.

\textbf{Problems That Arise in Canada}

What problems arise in Canada with allocating resources and distributing gene manipulations? It has been said that Canadians have accepted "less-than-optimal medical services, particularly the latest technological developments, in order that a basic level of care can be provided to all in need."\textsuperscript{235} In light of this, we ought to seriously re-think, or start to think about, how Canadians will provide the

\textsuperscript{234}ibid, xiv.

resources for gene manipulations.\textsuperscript{236}

It is not likely that the present system of Canadian health care delivery can distribute gene manipulations in a just manner. We are unable to deliver these services justly now. Deborah Jones indicates that Canadian health care is leaning increasingly towards privatization.\textsuperscript{237} With waiting lists for some present health care procedures, it is very likely that gene therapies will always be made available to a very select group. This opens the door for private clinics. The costly nature of health care indicates that only those with enough money could receive the benefit of gene therapies without the scrutiny of public health care.

Unrealistic Goals?

Are gene manipulations unrealistic in terms of resource allocation and just distribution? To attempt to respond to this question we have to consider two things; what our most important health care needs are and whether gene manipulations be used if provided. Daniel Callahan has indicated how medical services ought to be prioritized. He presents a model that focuses on "preventive health care,

\textsuperscript{236}The authors of Bioethics in Canada indicate that in the Canadian setting there are several things for governments to consider when allocating health care dollars for gene manipulations. Considering Canadians' acceptance of a basic level of care for all, rather than "high-tech" health care, there are various levels of care. A patient for heart surgery may wait up to six months or longer to have their operation. The level of care depends largely on the financial status of the patient. If you have the money you can go elsewhere to receive treatment. In deciding what medical services will be provided in our system, government identifies useless, harmful, and inappropriate treatments, it determines the effectiveness of treatments, and defines appropriate indications for each effective treatment. From this information government can "distinguish (1) treatments that are highly beneficial from (2) those that provide only marginal improvements in patients and (3) treatments that provide no improvement at all. Depending on cost considerations, governments can then provide funding for the first category of treatments, and perhaps some in the second category. All those in the third category would be deinsured."

basic medical services, and palliative care." This is a turning away from "high-tech" life extension and care for the terminally ill. Gene manipulations could fall into both categories. Somatic cell manipulations could be viewed as life extending treatments for rare genetic conditions and germ-line manipulations offer a potential form of preventative medicine.

Should we provide distribution of gene manipulations to all of the human community that is in need? I think the answer to this question is no because not all individuals and groups will want gene manipulations. Jehovah's Witness' decline blood products, and there is question in the Jewish community whether gene transplants are sex acts. Examples such as these are a strong indicator that not all groups will even want to have the technology at their disposal.

If there are groups within the human community that will not desire the effects of the gene manipulations proposed, who are these technologies aimed at benefiting? Furthermore, what lies behind the claims of great benefits to the human community? Health benefits? Select economic benefits? Is it even anticipated that we can meet the needs of the human population? It would appear that we intend to meet the needs of those individuals who can purchase the medical services offered.

I would argue that the cost of these therapies due to their experimental nature is far too high to warrant widespread usage with our economic resources. The Christian community, in particular, is concerned with serving the "needs of the weak, the sick, and the poor." Gene manipulations can serve the needs of the sick and the weak

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238Ibid, 348.

239Perlin, "Jewish Bioethics and Medical Genetics," 339.

by eliminating genetic disease. However, the poor will be neglected through genetic manipulation. Gene manipulations are unacceptable because they cannot be distributed justly. It would not be responsible to offer such technology to only those with enough money to purchase it, however, it is likely that gene manipulations will eventually be made available on a pay-per-use basis in private clinics.

6. Privacy and Confidentiality: Who has access to genetic information?

What does privacy and confidentiality entail when dealing with genetic information? We will discuss two elements of privacy and confidentiality that arise in the debate. The first is autonomy, the second is the challenge in keeping genetic information confidential.

Autonomy

The debate surrounding privacy and confidentiality revolves around personal autonomy and it is generally stated in the dialogue that the responsibility of sharing the information ought to be held by the afflicted person. Bruce R. Reichenbach and V. Elving Anderson advocate the notion that allowing the individual to control access to information promotes autonomy but at the same time autonomy is not the most basic value. They arrive at this conclusion because we live in communities and the information may have to be communicated to others.²⁴¹

Such persons might include family members and perhaps even employers. But if the information becomes known to others who have power over the afflicted, then social policies must be in force to protect and care for the person. The steward will see to it that those who are losers in life’s genetic lottery are given the dignity all stewards possess as beings valued by God.²⁴²


²⁴²Ibid.
In agreement with this, one group of religious leaders has suggested that an individual's genetic information ought to be "kept confidential and only be released with the full consent and awareness of the affected individual." However, the example of the sickle-cell trait that was pointed out earlier did not live up to the notion of maintaining personal autonomy regarding information. Afflicted people were still subject to discrimination when their confidential information became available to employers.

Keeping Confidential Information Private

We have good intentions to keep the information private and confidential but how do we accomplish this? This issue goes beyond the doctor-patient relationship. The Genome Project will open the door for increased information on the genomes of every individual. This is not to say that we are headed for some kind of genetic apocalypse but there are indications that we have to pay close attention to how we are going to keep this information if it is to be private and confidential. Archaic paper files can be lost, copied and burned. It seems to me that these would be the least of our worries in an age when information is retained in "cyber-space." How can we expect that any information is private if information it is retained "on-line" and readily available to anyone traveling in "cyber-space"? This


244 There are several articles that deal with this subject. Two are: James E. Bowman, "Genetic Screening Programs and Public Policy," Phylon 38, no.2 (1977):117-142; and Doris Yvonne Wilkinson, "For whose benefit? Politics and Sickle Cell," Black Scholar 5, no.8 (1974):26-31.

245 J.A. Lowden, of Crown Life Insurance, indicated in a recent conference (Genetics and the Law Symposium) that doctors tend give information quite freely. In the case of insurance companies this information becomes widely available to many.
presents a whole new forum for information passing hands and being lost.

Another question that can be raised is why we would want to maintain records of this information? Knowledgeable skeptics in pop-culture may question why the U.S. Energy Department (DOE) and the U.S. Department of Defense are involved in the Genome Project in the first place. They may wonder if it is not the government who want this information for some secret plot involving aliens. On a more realistic level we have to consider why there is fear of this information getting into the wrong hands. That fear is discrimination.

7. Commercializing our Genes: Patenting and Genetic Piracy

Is the patenting of genetic material an unacceptable procedure? In this section I will discuss patents and how they are viewed in law. I will also discuss cases of genetic piracy to show how patenting of genetic material can undermine a person's dignity.

Patents and the Law: protecting morality and human life?

In recent years there have been several applications for the patenting of gene sequences. The National Institutes of Health (NIH) in the U.S. applied for thirty-four gene sequence patents. All were rejected on the grounds that their claims were vague, lacked novelty and lacking utility, among other reasons. The goal of NIH, who work in conjunction with the U.S. Department of Defense, was to be able to "license its technology to industry." This

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246 I am referring to books and television shows depicting the plots of governments, from A Brave New World and 1984 to recent television shows such as The X Files.

type of licensing has been compared to computer software licensing.\textsuperscript{248} It is indicated that patents do not safeguard the public interest and are a tool of industry that "encourages innovation and [is] divorced from social and ethical concerns."\textsuperscript{249} However, Eileen McMahon indicates that without patents the transfer of research findings of universities and government labs to private business is not likely.\textsuperscript{250}

In Canada, the \textit{Patent Act} defines a patent as an invention as "any new and useful art, machine, manufacture or composition of matter, or any new and useful improvement in any art, process, machine, manufacture or composition of matter." McMahon points out that this definition would qualify a gene sequence as a new invention because it could be considered a "new and useful...composition of matter."\textsuperscript{251} However, further investigation of Canadian law indicates that while there is no mention of discovery in the patent act, case law restricts whether a discovery is inventive. McMahon cites several cases in the area of agricultural genetic manipulation to show how Canadian law restricts genetic discoveries from being inventions.\textsuperscript{252}

\textsuperscript{248}As the keynote speaker at the \textbf{Genetics and Law Symposium} at Osgoode Hall, Toronto, C. Thomas Caskey, MD., F.A.C.P Senior Vice-President, Research - West Point Merck & Co. Inc., made the analogy that gene sequencing licensing would be like computer software licensing.

\textsuperscript{249}Eileen McMahon, "Nucleic Acid Sequences and other Naturally Occurring Products: Are they Patentable in Canada?"

\textsuperscript{250}ibid, 4.

\textsuperscript{251}ibid, 5.

\textsuperscript{252}The Canadian Patent Office will accept genetic sequence claims only if they have industrial value. McMahon provides a list of what is and is not patentable in Canada in relation to genetic sequences. \textbf{What is patentable:} DNA, RNA and oligonucleotides, proteins and polypeptides, micro-organisms, unicellular life forms and viruses, cell culture media, processes to prepare, produce and isolate nucleic acids, polypeptides and micro-organisms, processes which use micro-organisms and diagnostic methods and kits. \textbf{What is not patentable:} higher life forms (plants and animals), natural biological processes and methods of medical treatment.
In the U.S., gene sequences are patentable only if they are "novel, purified and isolated sequences derived from the original gene in nature."\textsuperscript{253} The European Patent Convention (EPC) closely resembles the Canadian and American patent provisions. Like in Canada, they indicate that discovery does not connote invention but if the gene sequence is used to obtain a product beneficial to human beings and includes the production process for medicine it would be patentable.\textsuperscript{254}

International trade agreements such as the General Agreement on Tariffs and Trade (GATT) and the North America Free Trade Agreement (NAFTA), have provisions for excluding genetic sequences from being patented. NAFTA states that inventions can be excluded from patentability to protect morality, including to protect human, animal or plant life or health or to avoid serious prejudice to nature or the environment for reasons including the protection of human, animal or plant life, provided that the exclusion is not based solely on the grounds that the Party prohibits commercial exploitation in its territory of the subject matter of the patent.\textsuperscript{255}

Judging from the position of the international trade agreements and the patenting rules of various countries it would appear that governments are concerned with the dignity of human beings. This is congruent with various theological positions. Ted Peters reports that "scientists and governments around the world shout a resounding 'no!'"\textsuperscript{256} to patenting of human genetic sequences. Likewise, J. Robert Nelson indicates that the believing community holds "strong

\textsuperscript{253}McMahon, "Nucleic Acid sequences and other Naturally Occurring Products: Are they Patentable in Canada?", 17.

\textsuperscript{254}ibid, 18.

\textsuperscript{255}ibid, 24.

\textsuperscript{256}Peters, "Why genes and Theology?", 4.
opposition on grounds of divine creation, justice, and human life's sanctity." In addition, Judeo-Christian and other religious leaders denounced patenting of human genes, cells and organs because they are "creations of God, not [of] humans, and as such should not be patented as human inventions." 

I agree with the positions of the religious leaders and with the theologians. I also shout a resounding "NO!" to patenting on the basis that it will erode justice and life's sanctity in every way shape and form by reducing human beings to useful matter, in other words a commodity.

However, positions such as the one presented by NAFTA are questionable. The trade agreement indicates that patents can be rejected if they do not protect morality and human life and if this exclusion is "not based solely on the grounds that the Party prohibits commercial exploitation" of the particular gene sequence. What does this mean? It would appear from this statement that patents cannot be rejected on the sole basis of commercial exploitation. One could gather that an application for a gene sequence patent could not be rejected because of commercial interest. This presents a major challenge. In a world that is driven by economics and commercial industries what reason can we use to reject gene patents? Aside from our questionable laws, what structures are in place to ensure that human life and morality are protected?

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Genetic Piracy: Cases in Point

This raises further questions when we look at the issue of "genetic piracy." The Foundation of Economic Trends, made up of 35 nations, defines genetic or biological piracy as "making products that use genetic materials from Third World nations but without compensation." I expand the definition to include pirating information from anyone anywhere. I believe that a case can be made that this amounts to nothing more than the theft of an individual's, or group's, genetic information.

The case of John Moore, U.S. Patent No. 4,438,032, may be helpful to pursue this question further. Moore was treated for hairy-cell leukemia and had his spleen removed. He recovered but his doctor used his white blood cells to create proteins that could be used to treat "immuno-suppressive diseases." The sequence from Moore's spleen cells was sold to a biotechnology company for nearly two million dollars. The U.S. Supreme court ruled that when his spleen was removed it was no longer his property. Moore states that "what the doctors had done was to claim my humanity, my genetic essence, was their property. They viewed me as a mine from which to extract biological material. I was harvested." If you can't own your own spleen, what can you own? It appears that owning one's own genetic sequences is on shaky ground.

In the context of patenting, genetic piracy is used to refer to instances where there is profit to be made from a unique genetic sequence of an individual or group. One case where genetic piracy presents a challenge is with indigenous

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261 Ibid.
peoples. The Human Genome Diversity Project (HGDP) intends to collect and sequence genetic material from geographically isolated and linguistically unique indigenous groups. This type of information is already being collected by commercial biotechnology and pharmaceutical companies. Margaret Lock, a medical anthropologist from McGill University, points out that it is "inappropriate to liken indigenous peoples [or any others] to endangered flora and fauna to be captured and preserved through their genotypes." From my theological perspective, this is based on imago Dei and the sanctity of life. Furthermore I would argue with the principle of justice that there is a duty to ensure that the human dignity and lineages of these people are not endangered by large companies trying to exploit their genetic diversity.

Identifying gene sequences is a part of our quest for knowledge. However, I believe that patenting is more a plot to make money than an attempt to protect particular gene sequences. The World Council of Churches has this same position arguing that the patenting of human gene sequences reduces the concept of a distinction between what is living and not living. Even our patent laws use language such as usefully composed matter to reduce things that are patentable to a commodity. Imago Dei and the sanctity of life indicate that human beings, including the chemistry composing their genetic sequences, is more than usefully composed matter. It remains to be seen how permitting patents for human genetic sequences could uphold the sanctity of human life; the very thread that binds human


\[\text{ibid.}\]

\[\text{World Council of Churches, Biotechnology: Its Challenges to the Churches and the World, 22.}\]
beings. Regardless of whether one is Jewish, Christian, or a moral philosopher, the sanctity of life is disregarded by considering human beings as nothing more than usefully composed matter.

It would appear that the questionable language of the patent laws has the potential to erode human dignity. If there is no recognition of human dignity, human rights will be invalidated. It is one thing to have declarations of human rights written but a very different thing for humans to assert these rights. To ensure that we can assert our rights as human beings we have a duty to revere these rights when dealing with the patenting of human genetic sequences.

If we allow patents to be granted for human genetic sequences human beings will become little more than animated, and licensed, genetic mines. I would agree that there are bound to be positive outcomes from creating treatments for various diseases with genetic sequences. However, I think the patenting of those sequences does only two things: 1. creates the potential for selected groups to make a profit, and 2. reduces human beings to the same status as a computer program or any other compilation of useful matter. Justice will not be served by granting patents for human genetic material. I think that granting patents for genetic material is very dangerous because it reduces the human being to useful matter or a marketable commodity.

\[^{265}\text{See Daniel Callahan's "The Sanctity of Life."}^\]
Chapter Four: Where Do We Proceed From Here?

Judeo-Christian theological thought helps to elucidate an understanding of the issues of gene manipulation and the Human Genome Project by offering a basis of interpreting the issues with their varied theological foundation. I think this interpretation lies in *imago Dei*, the sanctity of life, co-creation/co-responsibility and justice. Drawing from this basis of interpreting various issues regarding human gene manipulation and the Genome Project I arrive at three basic conclusions.

First, we must recognize that regardless of whether we continue with scientific endeavors such as the Genome Project gene manipulations, there will always be a great fear of misuse. I think we have reason to fear that people in our society will want procedures like enhancement manipulations. This perpetuates a long standing fear, carried on by the survivors, of ‘genetic social engineering’ envisioned by Nazi Germany in the 1940s. However, we cannot discount gene manipulations based on fear. I think that widespread concern of the consequences of gene manipulation and the Genome Project act as a regulator of how we proceed. I think Judeo-Christian beliefs raise concerns of the consequences of gene manipulation. These concerns are evident in the principles I have presented: 1. Do gene manipulations change the human relationship with God?; 2. Will human beings maintain their sacred status?; 3. Are human beings responsible enough to carry out such endeavors as gene manipulation that will have an impact on future generations?; 4. Are gene manipulations just?

The second conclusion I arrive at is that the Genome Project and human gene manipulations are feasible but not legitimate. The Genome Project and gene manipulations can be defended both scientifically and ethically but I do not
believe that we can justify the vast amount of time, money and energy that we are putting into this endeavor. I believe that gene manipulations offer human beings an opportunity to do something that has never been achieved before; fixing a problem before it is started. This is supported by the notion of co-creation and co-responsibility. God has given human beings the ability to alter Creation and through gene manipulations this can be achieved. This is part of what makes human life special, no other species has the capacity to alter God's order at the molecular level. I believe the problem arises with the motives for altering God's order.

I think that altering God's order to gain profit or to eliminate a potentially useful gene from the human genome is a very misguided endeavor. I strongly believe that the interrelation within the universe, even within the solar system and beyond, ought to be treasured by humans because we can alter the very foundation of that system of interconnectedness. If we start to eliminate, turn on or off genes from the genome we may find ourselves in trouble. Given that human beings already alter the genomes of plants and destroy several species of plants and animals each day, I believe that altering the human genome may place an even greater weight on the interconnected systems of life on this planet. It will be like pulling another card from the bottom of a house of cards; we may get away with taking away one or two cards but at some point the whole house will fall. I do not mean to say that a genetic apocalypse is just around the corner but I do think that by removing unwanted genes from the genome we will affect the whole system. If these genes had no purpose why are they a part of God's order? I think that they have a greater purpose than to give humans an opportunity to alter God's order.
The third conclusion I arrive at is that the Genome Project and human gene manipulations raise a broad question of whether our goal is the quest to create a truly human community affirming each person's sacredness and dignity, including those marginalized because of genetic abnormalities, or the quest for material gain. The Judeo-Christian traditions that I have surveyed offer principles that can enable human beings to not only ensure that human life remains sacred but also ensure that we take responsibility for our actions and respect other human beings.

I believe one of the most important criticisms of genetic research and gene manipulations is that it creates a view of persons as nothing more than parts and pieces of a machine, much like patent laws would refer to gene sequences as useful matter. This criticism is evident in the arguments of one feminist group that indicate genetic technology and research are the result of a world view that perceives the world as a mechanism. They argue:

Just as a machine can be broken down into its components, analyzed and put back, living beings are seen as consisting of components which can be viewed in isolation. Aspects of nature which cannot be measured or quantified are seen as subjective and of no value and are therefore neglected. In their ignorance or disregard of the complex interrelationships in life, scientists collaborate with industry and big capital and believe that they have acquired the power to create and reconstruct plants, animals, other life forms and, possibly soon, even human beings. We oppose this patriarchal, industrial, commercial and racist domination over life.266

It should be clarified that not all scientists collaborate with industry and big capital.

One way to avoid this mindset is to look to other traditions and cultures for help. David Suzuki suggests that the idea of looking to other traditions and cultures

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for help in understanding these issues is not held in high regard by bioethicists from either the theological or philosophical camp.\textsuperscript{267} It would appear that we may have to look to alternative understandings of the world to assist our efforts of comprehending these issues.

Conversely the bioethical efforts of religious traditions and theologians verify their place in public discourse. Lisa Sowle Cahill points out that theological responses often do not possess a definitive "theological stamp" although arguments from particular theological strains of thought "give theology influence, even though this may not manifest itself in the explicit justification of moral conclusions."\textsuperscript{268} She says that bioethicists who arise from a theological perspective have been able to make bioethical interpretations without claiming that the specific themes of their faith commitments indicate specific decisions.\textsuperscript{269}

David Novak indicates that Judeo-Christian communities can "demonstrate to the larger world that their common approach offers a more coherent means for dealing with specific ethical questions than secular methods."\textsuperscript{270} He suggests that this can be achieved by offering a communitarian alternative from that of the individualistic approach of some secularists.\textsuperscript{271} Novak also suggests that before a religious community attempts to be influential in public dialogue it ought to have discourse with other

\textsuperscript{267} Suzuki and Knudtson, \textit{Genetics}, 338.


\textsuperscript{269} Ibid, 12.


\textsuperscript{271} Ibid, 19.
religious communities on the issues. Cahill and Novak point out that Judeo-Christian thought does have a voice in discourse although the religious underpinnings are not always evident. However, there are ways that the religious underpinnings of the theologians help to elucidate an understanding of the issues. From the theologians and traditions observed three pertinent themes arise that aid in an understanding of the issues surrounding human gene manipulation and the Genome Project. The first is that human life is sacred because it is created in God's image. The second is that we have an ability to alter God's order. In this case we have the ability to change the human genome. The third theme is: because we can alter God's order, the human genome specifically, we have a duty to ensure that human life is kept sacred.

These themes help to formulate an understanding of gene manipulations and the Genome Project. How do they do this? They act in a reciprocal manner; each relies on the other. The first theme affirms that human life is sacred based on a religious conviction; God is the creator of human beings and because of this human life is sacred. The second theme helps us to grasp that humans have the God given ability to alter the human genome. The third theme returns to God what we were allotted in Creation; sacredness. However, humans must ensure that this status is maintained because we have taken the responsibility of creation.

Where can we Proceed from Here?

Theological thought helps us to form an understanding of the issues of gene manipulation and the Genome project by offering interpretations based on individual faith commitments and particular themes that arise from these faith commitments. Judeo-Christian theological thought has
a familiar voice that does have an impact in the debate of these issues but there may be alternative routes that it can travel to further accommodate the faith communities' understanding of the issues. How can theological thought do this? One way that this could be done is by examining issues, like the ones we have presented, and showing how they can help us to better understand our faith communities. Perhaps these relatively new considerations in science can aid the Judeo-Christian community in asserting or redefining its notions and beliefs.  

I would argue that the issues I have discussed present the opportunity to closely examine our beliefs. Why is it that in the theological dialogue abortion is viewed as the be all and end all of screening for genetic illness? I think that attitudes such as this are very limiting. I think that we have to be open to new possibilities such as gene manipulation. I believe that we have a duty to consider to have children with genetic abnormalities. Through giving this child whatever life it may have love will be the result. I think that we have to consider what these children and people have to offer those in society who deem themselves normal. "Normal" people use only a small portion of their brains, perhaps these people we shun and do not want in our society use a part of their brain we cannot imagine using. I believe it is important to open our hearts and our minds to the people with genetic abnormalities and those not yet born. Instead of seeing these people as a financial, or other, burden I think we need to reconsider what it is we value. I argue that our basic human value is respect for human life and the precondition for all other values.

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272 One such case may be the recent identification of a "gay gene" in men. Discoveries such as this make it probable that some religious traditions will have to reconsider their stance on homosexuality, considering its genetic predisposition.
Summary

Through tracing the history of genetic science up to the Human Genome Project I elucidated an understanding of how we got to the Genome Project. Continuing this study with an in-depth look at the Genome Project I was able to better understand the scientific processes of mapping and sequencing. These technologies are important to comprehend because the knowledge that these processes divulge is expected to have vast implications for future discoveries in science and medicine. With an understanding of the Genome Project and subsequent technologies I raised some ethical issues that present challenges for theological thinkers.

Observing varying religious thought regarding gene manipulation from the Judeo-Christian tradition I was able to identify certain themes that were evident. First I examined the early views of Rabbi Immanuel Jakobovitz, Joseph Fletcher, Paul Ramsey and Charles Curran. From the differing perspectives of these theologians I was able to gain an understanding of the foundation of later theological positions. I also looked at the most recent statements of the Catholic, Anglican, United Church of Canada, and Judaism. As well, current statements from the World Council of Churches (WCC) were investigated. I gathered certain themes from the positions of the theologians and traditions. I align these themes with my own theological perspectives. Through surveying further theological insights I support my own theological convictions: 1. God permits me to live and because of this my life is sacred; 2. I live my life to do the works that God has planned for me (this may include genetic engineering); 3. in doing these works I am fulfilling a responsibility to other human beings; and, 4. the result of these works is love. These theological convictions result in hermeneutical principles that give me
a foundation to enter the theological debate on the ethical issues. These principles consist of the doctrine of *imago Dei*, the sanctity of life, co-creation/co-responsibility and justice.

In the third chapter I examined and responded to the theological debate on the ethical issues of human gene manipulation. The issues I interpreted and responded to were genetic screening, enhancement manipulation, eugenics, genetic discrimination, just distribution and resource allocation, privacy and confidentiality, as well as patenting and piracy of human genetic material. From entering this conversation some theological reflection has been discussed. This aids in arriving at the main goal of this project; determining how theological thought helps to elucidate our understanding of the issues of human gene manipulation and the Human Genome Project.

I argue that *imago Dei*, the sanctity of life, co-creation/co-responsibility, and justice are the basis of Judeo-Christian interpretation of the issues of gene manipulation and the Human Genome Project. As a result of interpreting various issues from this basis it is concluded that there will always be fear of misuse of gene manipulations, the Genome Project and gene manipulations are feasible but not justifiable and a broad concern of the motives behind the Genome Project and gene manipulations is raised.

**Conclusions**

The Judeo-Christian traditions offer a wealth of material regarding the Human Genome Project and human gene manipulation. I have indicated the positions of various theologians and traditions. Their positions offer a rich theological foundation for investigating the issues of the Genome Project and human gene manipulation. Although the
theologians and religious groups I present have definitive positions on the issues, I think it is difficult to state a definitive position. From a broad perspective, the difficulty is a result of points of tension that I feel arise from the presence of both positive and negative implications of the Genome Project and gene manipulations.

I think part of the challenge of arriving at a definite conclusion regarding the issues lies in defining the conversation as theological. If the discussion is theological, as it is in this thesis, then the conclusions made by the participants in the discussion will arise from their faith commitments. Because I have not defined my own theological faith commitment, I cannot make any specific conclusions at the present time. Once I define my own faith commitment, or decide to discuss the issues from a philosophical perspective, I will be better able to present a bottom-line stance on the issues regarding the Human Genome Project and human gene manipulation.
Bibliography


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