EFC The Evangelical Fellowship of Canada

Changing Genes:

A Christian Approach to Human Genetic Testing and Therapy

October 11, 1995

I. Introduction

At the beginning of the 20th century, human genetic research was in its infancy. Today, our society is in the midst of a genetic revolution. Hardly a week goes by without media reports of the discovery of a gene that is thought to be responsible for some disease or some aspect of human behaviour.

This is largely the result of a massive research endeavour called the Human Genome Initiative, a collaborative effort by scientists from around the world to determine the genetic blueprint of human beings. Scientists currently estimate that they will be able to locate and identify the estimated 100,000 genes that comprise the human genome by the year 2003. Related research projects are also underway to identify specific alterations or variations in the human genetic code (called gene mutations) which are responsible for the inheritance of genetic diseases. Various testing procedures are already available to detect some of these genetic conditions, with development of more extensive diagnostic tests being planned for the future. This research may eventually lead to the development of successful treatments for diseases associated with genetic disorders.

These new discoveries may offer great hope to those who suffer from genetic diseases. But they also generate a number of ethical, medical, legal and theological issues which should be of great concern. Scientific and technological projects in the field of genetics provoke us to ask fundamental questions about the very meaning of genetic "disease," about our readiness to value people unconditionally, and about the relationship between technological "progress" and the Christian hope.

There are questions about the extent to which humans should intervene in the genetic makeup of an individual. Some people think that the crux of genetic technologies is the attempt of some to "play God." They believe that the use of genetic technology will alter the root of who God created us to be. Other people believe that we are created to be co-creators with God, and to refuse to re-engineer genetic abnormalities is to neglect to help one's neighbour.

Within the context of one's theological understanding are also the ethics and medical dynamics of how Christians can minister, given the pervasive presence of genetic technologies. How do Christians respond when they discover someone close to them has a high probability of displaying a genetic disease, or a significant probability of passing a genetic disease on to the next generation? Prenatal testing for genetic disease traits often leads to selective abortion. How does a Christian respond? Testing for diseases that will develop early in life, or predicting diseases that will develop later in life, also gives rise to issues of privacy and discrimination. For example, will insurance companies grant life or health insurance to a person with a high probability of developing breast cancer or colon cancer?

Human genetic testing raises again the question of what it means to be a Christian living in a technological age which tends to regard technological "solutions" as the best way to respond to social and individual ailments.

Christians must be informed about each of these issues and be ready to enter into public debate about the use of genetic technology, as well as being prepared to deal with the implications of this technology that will inevitably affect their own lives. Among the doctors who are treating people with genetic problems, there are providentially many Christians. The same is true among the scientists who are making the new discoveries in genetics. But we must not be naive. Genetics is a field in which the clash between a biblical and a non-biblical worldview can be very direct. A non-biblical perspective

might see disease as the greatest evil and the elimination of disease (or the creation of a genetically perfect humanity) as the greatest good. From such a perspective genetics could be seen as possibly the most promising weapon in a war to eradicate all that is wrong with humanity. For Christians, however, the love of God is the greatest good; we live and die within God's grace; from this flows everything else. The Christian challenge in genetics is the same as it is elsewhere "to take captive every thought to make it obedient to Christ." (2 Cor. 10:5)

This paper has been published with the purpose of providing members of the body of Christ with 1)biblical principles that have an important bearing on the evaluation of genetic technology 2)basic medical information related to genetics, 3)an introduction to the ethical, legal and theological issues that result from the use of genetic technology and 4)practical suggestions for ministering to those affected by genetic disease. It is hoped that this information will not only stimulate understanding, but also provoke discussions that will shape Christian attitudes, values and responses to the use of genetic technology. The authors encourage the reader to consider this information in a prayerful manner, attempting to discern how God would have Christians be "salt and light" and compassionate communities responding to the issues raised by genetic technologies.

II. Biblical Principles

The Bible does not deal directly with issues related to genetic testing and therapy. However, there are Biblical principles which Christians can use to evaluate these contemporary issues. These principles include: the sovereignty of God, the sanctity of life, the dignity of the person, compassion, justice in community, good stewardship, living as people of hope and resisting the temptation to usurp God's place.

We begin with the conviction that God is sovereign--that the world and all that is in it belongs to God. God, and God alone, is the creator; human beings are His appointed stewards, charged with the responsibility of using the gifts we have been given in ways that honour God and acknowledge our accountability to Him. Genetic research potentially offers humans the **power** to tinker with, and reengineer the fundamental building blocks of life, and the utilization of such powerful technology raises legitimate concerns about whether it will encourage human beings to regard themselves as the creators of life, rather than the caretakers of it.

The Bible teaches that children are to be received as gifts from the hand of God, not "projects" of our own making. This principle applies not only to the relationship of parents with their children, but also to those who hold the power to reshape future questions through genetic "engineering."

As Christians, we believe that human beings are created in the image of God, and therefore have inherent dignity and worth. Life is sacred and should be cherished. There is no such thing as a "useless" life because our worth is not determined by what we can do or accomplish, or even by the pleasure we experience; but rather by who we are in relation to God and each other. We therefore believe that human life must be valued, respected and protected through all its stages. This principle is unchanging and holds true for every human life. The dignity that belongs to human life belongs equally to people with and without genetic diseases.

The Bible also clearly demonstrates that suffering is often a part of human existence. Try as we might, human beings lack the ability to prevent or eliminate it all. Sometimes our well-meaning efforts to minimize suffering in one area create pain, hardship, or injustice elsewhere. So, while it is our responsibility to attend to human suffering, and while healing is a godly vocation, it is not our duty to rid the world of all suffering.

The causes of illness, disability and suffering, and the reasons for which God allows them, are often shrouded in mystery. Frequently, the full meaning of an individual's challenges is worked out not only in the living of the person's own life, but also in the lives of those who provide care and have contact with him or her. We do know that for many their experience has been a door into communion with God rather than a barrier.

The importance of human community is also a significant part of Biblical teaching. From the beginning, it has been God's purpose to call into existence a community that acknowledges His Lordship and practices faithful love towards each other.

Our generation may have the unique opportunity to use genetic research, testing and therapy as new avenues by which Christians can demonstrate compassion and love. However, as Christians, we also have a responsibility to be vigilant in protecting humanity from the possibility of being abused by the use of this technology. We must

ensure that people with genetic disorders are neither exploited for scientific or commercial advantage, nor discriminated against on the grounds of their differences or "abnormalities."

As will be pointed out in the next sections of this paper, people who have a genetically-linked disease or carry genes for genetic diseases are at risk for being treated unjustly. The Bible teaches us that God is a God of justice, and is opposed to the oppression of the poor by the rich, and the weak by the strong. The development of genetic science poses a new challenge to the church and to our society to live out this Biblical principle, and to ensure that genetic testing and therapy are used fairly and without abuse.

Genetically-based disability or disease is not sin, and genetic therapy is not salvation. It would be idolatrous to think that genetic discoveries could eliminate all the problems in the world. The God who is the creator and governor of the world is also its only Saviour. This conviction should help us to keep any enthusiasm about genetic technology in proper proportion.

Lastly, Biblical theology is a theology of hope. But, hope, as Christians mean it, is not not always the same as "cure;" and it is grounded in the changeless love of God, not in changing technology. Consequently, this distinctive hope is particularly significant in helping Christians understand and live with genetic disease. (Section V of this paper lists numerous practical Christian responses to the reality of genetic disease.)

III Brief Primer on Genetics, Genetic Testing and Gene Therapy

In order to understand the enormous impact of genetic technology on our society and the potential benefits, harms and limitations that it will have on individuals, families and medicine, we need to have a basic understanding of some of the scientific principles related to its development and use.

Genetics is the study of heredity, or the biological characteristics that are passed on from parents to children. Thousands of characteristics or traits, such as eye colour, hair colour and height are known to be passed on to the next generation through genetic material. However, "mutations" in the genetic material can also cause certain diseases to be passed on or inherited. Currently more than 4000 diseases, including cystic fibrosis, muscular dystrophy and many forms of mental retardation, are known to be caused by genetic mutations. Other common conditions such as heart disease, hypertension, diabetes mellitus and cancer are also known to be influenced by an individual's genetic makeup as well as environmental factors.

A. What are genes?

Genes are the chemical units of heredity that are sometimes referred to as the "blueprint of life," since they carry instructions for making all the proteins in the cell and therefore provide the blueprint for the biological changes and development that occur in each individual. Genes are actually subunits of DNA (deoxyribonucleic acid), which is made up of chemical building blocks called bases (adenine, thymine, cytosine and guanine). Scientists estimate that there are approximately 100,000 genes in the human genome, made up of three billion bases. The order of these bases determines the message that the gene carries, just like the letters of the alphabet combine to form words and sentences. A gene, therefore, contains a sequence of DNA that provides the code for making a specific protein or part of a protein that is necessary for our body to function (see Figure 1).

The chromosomes are arranged in pairs and each half of the pair contains an almost identical copy of the DNA. In humans, there are 46 chromosomes in each cell, arranged in 23 pairs, containing the genetic instructions for that individual (see Figure 3). Egg and sperm cells (often referred to as germ cells) are unique in that they contain only one chromosome from each pair or 23 chromosomes in total. This ensures that when the egg and sperm combine, the child will have the right amount of genetic material--half from the mother and half from the father. This combination of chromosomes from both the mother and father also accounts for the "genetic uniqueness" of each child.

B. How are genes related to disease?

Many diseases are due to mutations which can occur in the DNA sequence. One common mutation results when the order of the DNA bases is altered, resulting in a "misspelling" of the DNA message. In other mutations, known as deletions, some parts of the DNA message may actually be missing.

Mutations can be inherited from one or both parents who carried the mutation themselves, or can occur

spontaneously, resulting in a "new" mutation. When the "new" mutation occurs in the egg or sperm cell, it is referred to as a germ cell mutation. When the "new" mutation occurs in cells other than the egg or the sperm, they are referred to as somatic cell mutations.

Mutations can be dominant (where only one gene in a pair is altered) or recessive (in which both genes in the pair are altered). In a dominant gene mutation, only one of the parents is affected and therefore, there is a 50% chance of this mutation being passed on to offspring (see Figure 4). Recessive gene mutations result when both parents carry the same altered gene in the pair, and both pass the altered gene to the child. When the mutation is recessive, the parents are usually unaffected by the disease since the other gene in the gene pair is normal. The chance of two carriers of the same recessive gene having an affected child is 25% (see Figure 5).

But no matter how or where the mutation occurs, it always results in the creation of an abnormal protein or causes the absence of a protein, which then causes some type of abnormal cellular function. This abnormal function can lead to certain diseases, but the type of disease which results is determined by which genes are affected by the mutation.

For example, if a child has two copies of the cystic fibrosis gene mutation, which is a recessive gene, the child will develop the disease. However, if the child receives one normal gene and one mutated gene, the child will not develop the disease but could potentially pass it on to any offspring. In other diseases, the effects of genetic mutations are less predictable in their effect on an individual. For instance, 15-20% of women who carry the gene that makes them susceptible to breast cancer (known as BRCA1 or BRCA2) will not develop breast cancer. In these cases, other genes and environmental factors also influence whether or not the disease will develop.

C. What is genetic testing?

Genetic testing usually refers to testing an individual's DNA for mutations that could cause a genetic disease. DNA is extracted from cells taken from a blood or skin sample and then the chromosomes are examined for abnormalities. Tests can also be done to detect the presence or absence of a particular protein, since this could also signify the presence of a mutated gene.

Many genetic diseases currently can be detected by genetic testing and it is thought that, in the future, specialized blood tests will be used to identify an even greater number of genetic disorders--perhaps even before the disease is expressed.

D. How can genetic tests be used?

Genetic tests are used most commonly to confirm the presence of a particular genetic disease in an affected individual. But individuals who are at high risk for being carriers of a particular disease may also undergo genetic testing to determine if they are carriers of genes that may lead to disease in their children. A third application tests individuals to predict their chances of developing a genetic disease, such as Huntington disease, later on in life.

E. What are the benefits of genetic tests?

Individuals who suspect that they are at high risk of developing an inherited disease often live with troubling uncertainty. A negative test can confirm that they are not carriers for a particular gene and therefore have a negligible risk for developing the disease. This often leads to a tremendous sense of relief. A positive test, which indicates that an individual carries the affected gene, can still be beneficial in that it allows an individual to make an informed decision about future medical care and lifestyle changes which may prevent or modify the expression of the disease, as well as decisions about career goals or family planning.

F. What are some of the risks of genetic tests?

Individuals can experience a significant psychological impact with either negative or positive gene test results. Depression and despair can result when an individual finds out that he or she carries a particular gene mutation, but it can also accompany the apparent good news of a negative test! Sometimes when an individual finds out that he or she does not carry the gene, he or she will feel guilty about being spared while other members of the family have the gene and develop the disease. This is referred to as "survivor's guilt."

In addition, the knowledge that an individual carries a gene that predicts disease can lead to other problems such as discrimination in such areas as obtaining employment or health insurance (these issues are dealt with in greater detail in Section IV of this paper).

G. What is gene therapy?

Gene therapy involves the transfer of genes carrying the correct genetic message into defective cells to restore the proper function of the cell. These techniques are currently experimental, but eventually may be used for the treatment of selective genetic diseases. Researchers are currently using gene transfer technology to treat individuals with cystic fibrosis, inherited diseases of the immune system and some forms of cancer. At this time, such treatments are restricted to somatic (non-reproductive) cells where the resulting corrected cells cannot be transmitted to future generations.

In germ line therapy, genes are transferred into an early embryo, thereby modifying cells that are not yet committed to develop into specific organs and altering the messages carried by the germ or reproductive cells. The gene therapy may correct the underlying genetic disease, but because it alters the germ line, any changes will be transmitted to future generations. The risks of permanently altering germ cells that can affect future generations are currently unknown and therefore germ line therapy is very controversial. Inserting the normal gene into other genes may cause damage which could result in undesirable or unexpected secondary effects. Germ-line therapy could also inadvertently lead to other gene mutations or irregularities that could cause cancer, developmental defects and/or other undesirable states which would then be passed on to future generations.

However, it is also argued that if the technology for gene therapy is eventually proven to be safe, then germ line therapy to correct the disease would serve to benefit future generations of individuals who would otherwise develop the disease.

IV. What are the Issues?

The issues related to genetic testing and therapy are complex and heart-wrenching. They require discussion and a prayerful consideration of the facts and realities before we, as Christians, respond. However, as stated in section II**,** there are a number of Biblical principles that can guide us in resolving some of the concerns that we have about the use of genetic technology.

In general, the concerns about genetic technology can be identified through four broad, overlapping, categories: medical, social, legal and pastoral (see Section V) issues.

A. Prenatal Genetic Testing and Abortion

The most-publicized concerns about genetic technology are related to medical issues such as the merits of prenatal diagnostic testing and the limited options that are available if a positive test results. At present, very few genetic abnormalities can be treated prenatally, and even fewer corrected. Therefore, a woman who chooses prenatal testing and is found to carry a child with a genetic or birth abnormality, usually has only two options available to her--to keep the child or have an abortion.

Prenatal diagnostic testing is widely available in Canada and involves the use of procedures such as amniocentesis, ultrasound and maternal blood testing. Amniocentesis is an invasive testing procedure occurring 16 to 18 weeks into pregnancy. It is strongly advised only where it is believed that there is a high chance of a genetic abnormality being present in the unborn child (as in the case of those over 35 years of age who have a greater chance of having a child with a chromosomal abnormality, such as Down Syndrome) since there is a 1/200 chance of an unintended miscarriage occurring due to the procedure.

However, despite the risks, there is still a tremendous amount of pressure placed on women at risk to have prenatal tests to detect the presence of genetic mutations such as cystic fibrosis (CF) in their unborn children. If a baby has one of the several hundred genetic mutations associated with CF, he/she will develop the symptoms of CF and likely have a shortened and difficult life. One option given to the couple is that the fetus be aborted. Researchers are working to identify and repair the genetic mutations that cause this disease, but legitimate concerns can be raised about offering prenatal tests for such diseases when there are no cures available and abortion is the only option that is offered.

There is significant evidence that some couples, and particularly women, suffer grief following the abortion of a child. This grief is characterized by sadness, depression, anger, fear, guilt, failure, shame, isolation and panic attacks. Some women may initially experience relief, but studies with long-term follow-up (after 24 months) show that symptoms persist and an undetermined, but significant number of women suffer from post-abortion grief. These women need supportive counselling, intervention and an opportunity for emotional and mental healing through the grace of our Lord, Jesus Christ.

Biblical precepts clearly favour life over death, and protection of the weak and the disenfranchised. The unborn child is a creation of God, made in His image, and with a planned purpose. Aborting unborn children because of inconvenience, as a means of birth control or to select fetal sex is unacceptable to most Canadians regardless of their religious persuasion. But there is increasing tolerance of a policy of aborting unborn children that are genetically abnormal.

Prenatal diagnosis does have some benefits. Testing may assure a couple that their child is likely to be healthy and this can relieve distress and reduce anxiety. As well, the prenatal identification of a baby with a genetic or other birth anomaly can allow the couple to begin grieving the loss of the expected normal child, to prepare for the delivery of an affected child and to facilitate counselling and contact with other community or disability support groups. In this way, prenatal testing can allow the couple and family to celebrate the child's birth, in spite of the anomalies, since the shock of the diagnosis would have abated.

There is also evidence that prenatal testing can be lifegiving. Many couples known to be at a high risk of having a child with a genetic disorder would decide against future child bearing if they did not have the opportunity for prenatal testing. However, it is clear that the life-giving value of prenatal diagnosis in this situation is potentially at the expense of affected fetuses being aborted.

Some families who have been affected by the shock of having a genetic mutation diagnosed prenatally have said that health care providers did not give them enough information prior to testing and that the advice given after the diagnosis was strongly biased towards aborting the fetus. All medical procedures should be voluntary, and health care providers are required by law to provide full information about the tests and the possible outcomes. Consequently, the Christian community must work to ensure that all genetic testing is voluntary and offered only in the context of full information. Since a bias towards aborting affected fetuses can subtly be built into the training of genetic specialists, ensuring the voluntariness of testing may not be enough, however. We must also find ways of removing or resisting the presumption favoring abortion.

It should also be remembered that people who carry genes for genetic diseases or have genetically-linked conditions which are regarded as disabilities are vulnerable to the influence and advice of the medical community, as well as to the perceived wishes of their families. They need our compassion and counsel in making hard decisions, and our compassion should not be affected by the choices they make--particularly in terms of keeping or aborting an unborn child.

B. Eugenics

The issue of eugenics is a vexing one for many geneticists. They want to distance themselves from the historical context in which eugenics was promoted as a way of "improving" population health. In the name of eugenics, those deemed genetically "unfit" were forcibly sterilized or worse. Sometimes called "negative eugenics," such practices were not confined to Nazi Germany, but were advocated by leaders in medicine and social policy in North America too.

Some researchers and specialists in the field of genetics argue that the information and new technology resulting from the Human Genome Initiative and current genetic research promote the enhancement of the genetic qualities of the population (referred to as positive eugenics). Although it is highly unlikely that genes to enhance intelligence, looks and personality could be brought together to develop an "ideal human"--since most of these traits are not determined by one gene, but by several genes and also by a host of environmental factors--this does not mean that no one will be interested in trying.

We can be thankful that most physicians and geneticists involved in DNA technology today are motivated by the desire to treat diseases caused by gene mutations, not the more troubling practices of negative or positive eugenics; but the potential for the technology to overtake their motivations cannot be ignored.

Perhaps a starting place for the Christian is examining how our social context shapes and is shaped by our beliefs.

C. Cloning

Cloning is the idea and practical means of making genetically identical human beings. Concerns about cloning were recently sharpened with the announcement that a sheep (named Dolly) had been produced by combining a mammary cell from one adult sheep with the

unfertilized egg of another sheep. The fused product developed into an embryo which was then transferred into the uterus of yet another sheep who served as the surrogate mother. Until this development, the only successful cloning of animals had resulted from a forced twinning of animals still in their embryonic state.

Whether techniques which have been successful with sheep will be applicable to other animal species, including humans, is unknown at the present moment. But the very nature of scientific investigation will compel scientists to try to replicate the experiment and extend its application.

Most Christians**,** as well as the population at large, find cloning in general, and the cloning of humans in particular, repulsive. Ethical justification of this sentiment must rest on a fuller understanding of the biblical principles referred to earlier. In this manner, the Christian is fully equipped to offer witness in the public sphere to God as a God of hope, who uses but is not dependent on our technologies.

At the same time, we should also understand that for many scientists, the most exciting thing about this latest cloning discovery is not what it proves about cloning, but rather what it teaches about basic cell biology, perhaps offering new cures for old genetic diseases. Society's vigilance is still required and it is clear that restraints and regulations will be required at some point in the future to prevent the possible abuse or misuse of this technology.

D. Discrimination

One thing genetic technology must not be used for is the "elimination" of persons, born or unborn, on the grounds that they have a genetic disorder which would be costly for society to care for.

Many individuals fear that the selective abortion of fetuses with mutations will lead to discrimination against those individuals who are born with genetic or other birth anomalies. Certain genetic disabilities and diseases take a heavy financial and emotional toll on families and communities, and it is easy to think that it would be better for society not to have to care for individuals with disabilities.

The disabled community fears that as greater funds are directed towards the development and utilization of prenatal testing, there will be fewer resources left for the care and treatment of disabled individuals. In Canada we all recognize that health resources are currently stretched to their limits within constrained budgets. But we also have a responsibility to advocate for balanced allocations of health care resources. We must ensure that funding for the care and treatment of the disabled is not diminished as a result of increasing funding for genetic therapy and research projects.

The Human Genome Initiative will yield a mapping of the "normal" human complement of genes. But no individual is expected to match the map exactly; we all have variances from the "norm." This very way of putting it has the potential to redefine the concept of "disease." Will a person count as diseased, abnormal if it is discovered, for example, that he has genes linked with a propensity to violence? Historically we have treated the "disabled" and "diseased" differently from the rest of society, and not always for the better.

E. Denial of Insurance and Health Coverage

Even before genetic testing was widely available, the medical community was aware that some diseases were genetically linked. Simply stating that one of these diseases was present in a member of your family could lead to a denial of health or life insurance. Now that genetic testing is more widely available, what will be the consequences for such things as insurance, employment and availability of health care? Will insurance companies use this technology to identify genetic mutations in unborn babies and refuse to provide coverage based on prenatal screening?

There are a variety of genetic mutations that do not manifest themselves for many years. Among these are Huntington disease, Amyotrophic Lateral Sclerosis (also known as Lou Gehrig's disease or ALS) and some forms of breast cancer (BRCA1). If a person carries the genetic mutation for one of these diseases, it is almost certain that the person will develop that disease at some point in life. A person with Huntington disease, for example, usually develops symptoms between the ages of 35 and 45, while a person with the BRCA1 gene is at a high risk of developing breast or ovarian cancer by age 40. If there is a family history of these diseases, life and health insurance companies will often deny coverage.

At the present time, there is very little protection for individuals and families who carry these various genetic mutations. While provincial human rights codes protect against "discrimination on the basis of physical

disability," there have so far been no cases interpreting that to include genetic "disability." This means that insurance companies and employers currently can discriminate legally against those known to have or to be at risk of developing an inherited diseases.

There are several notable complications that are associated with this type of discrimination:

Firstly, we are all genetically programmed to die. In fact, our genetic composition makes us more susceptible to some diseases. If general genetic testing becomes available and tests are able to detect a broad range of diseases and conditions, it is likely that many people will be unable to get insurance. Secondly, insurance companies do not discriminate on the basis of lifestyle, with the exception of smoking tobacco or engaging in certain high-risk recreational activities. Insurance forms do not ask whether you get regular exercise or eat a low-fat, high-fibre diet. A person with no family history of any particular disease may still die at an early age for any number of reasons that are not part of the insurance screening process. Thirdly, the philosophy of insurance is to even out the risk of early death. If insurance companies are permitted to screen out individuals at high-risk for early death, that lowers the insurance companies' risk while leaving many people without any insurance.

If a person has a family history of a particular genetically-linked disease, insurance companies may require that applicants have a genetic test to confirm whether they have that gene. This can be very stressful for the individual. The applicant may not want to know ahead of time if he or she carries that gene, and there can be negative consequences for either a positive or a negative test result. If the test is positive, showing that the person carries the gene for the disease, the person can suffer depression and have suicidal tendencies. If the test is negative, the person can suffer from "survivor's guilt," especially if he or she has watched family members suffer with the disease.

F. Employment Issues

Should employers be able to discriminate on the basis of genetic testing? Employers may be concerned about hiring individuals at high risk of developing a genetically-linked disease for several reasons. Firstly, employers do not want to have to deal with employees who need special assistance due to disease or disability. Secondly, employers are concerned about having a drain on the company health insurance plan and thirdly, they do not want employees who are, or could potentially be, unproductive due to disease.

But should employers be able to require prospective or current employees to be screened for genetic anomalies which might impact the employee's future job performance? No employee comes with a lifetime guarantee and employers are currently not permitted to deny a person employment on the basis of a physical or mental disability unless it makes the person unable to do the job.

G. Privacy and Confidentiality

As genetic testing becomes more readily available, it also raises issues of privacy, such as:

Who should have access to the results of genetic tests? If an individual undergoes genetic testing for the purposes of making lifestyle changes, should that information be available to potential employers or insurance companies? Should genetic testing be available to other family members who might have a similar genetic mutation? Should it be available to a potential spouse of the person whose children might be affected?

Currently, medical information is confidential between the patient and the caregiver. Unless specific consent is given for some other use, such as research, medical information can only be used for the purposes of treatment. Therefore, before the information can be released to another person, the patient must give written consent and it is up to the patient to divulge any information to other family members or friends. However, many employers and insurance companies now insist on having this information before they will give employment or insurance.

The issues of privacy and discrimination will become increasingly complex as more genetic testing becomes available. If genetic screening is advised by your doctor, you may wish to inquire about the privacy of the test results before consenting to the test. Some testing facilities will keep results of genetic tests in separate files, apart from your general medical records. In addition, if you are taking part in a medical study, you may wish to ensure the confidentiality of the results before consenting to take part in the study.

On the level of social policy, questions should be asked about the ownership of genetic technology and the information gained through research and rights of access to therapies. Because much of the genetic research is being undertaken or funded by private companies, there are pressures to commercialize this knowledge and to cover innovations by patent laws. Should this be acceptable to Christians or should we find this in conflict with biblical principles of stewardship and of care for people on the basis of their need, not only their wealth?

H. Legal Issues

What limits should there be on genetic research and testing? Who should make and enforce them? Is this a role for the government, for hospital ethics committees or for professional associations? The laws of a country reflect the moral framework that underlies the interactions of the individuals within a society. In a more subtle way, the law also acts as a teacher, shaping and influencing how individuals view a specific legal or moral problem. Some feel that there should be strictly-defined laws dealing with the issues of genetic testing, both pre- and postnatally, and all other aspects of genetic engineering prior to the technologies being introduced into Canadian society. This approach would seem to suggest that the laws dealing with these areas will reflect the values and beliefs of Canadians and therefore codify the legal and ethical behaviours prior to the introduction of the technology.

Another approach would allow the regulation and control of these technologies to be left in the hands of the health care or the biotechnology industries. This approach suggests that no laws are needed, or that if laws are necessary, they would only serve to ease the introduction of genetic technologies into society, and hasten its acceptance by society.

Given what has been said previously about the application of Biblical principles in this area, we believe that the laws of Canada should demonstrate a clearly articulated position favouring the inherent worth and equal protection of all people. The law should provide for distinct protection of human beings based on the principle of sanctity of human life and should acknowledge that mankind is created in the image of God. This does not rule out the use of, or eliminate the development of, genetic technology applications. It does, however, place the context of the use of genetic technology within the larger framework of a Biblically-informed worldview.

This approach would imply that certain applications of genetic technologies would be prohibited or strictly controlled, such as the cloning of human beings, the creation of human-animal chimeras (hybrids) or the development of "eugenic gene therapy" which would attempt to enhance certain human traits such as intelligence or appearance. The development of other applications, such as predictive genetic testing, may be limited until it can be determined how society will react to the availability of such information. The introduction of genetic screening into the life insurance industry may be an example of such an application. The use of other applications of genetic technology, such as using genetic technology for the production of human insulin and other hormones, is already well established and regulated and may not need further control.

The assertion that a biblically-informed world view be used to frame the debate surrounding the development and introduction of genetic technologies will not be accepted in many circles. However, the legal and judicial systems in Canada have, until recently, used this world view to frame their discussions and develop the laws we live by in Canada. The issues which were previously mentioned, such as the integrity of the person, privacy and confidentiality, can be adequately and comprehensively addressed within the context of a Judeo-Christian world view. Implied in this discussion is the view that legislation is, and will continue to be, necessary to protect the individual and his or her genetic inheritance from the incursions of the medical, insurance and industrial establishments.

Prior to the 1997 election, the Canadian government had taken some steps towards regulation in genetics, guided by some of the recommendations of the Royal Commission on New Reproductive Technologies. Legislation was introduced prohibiting such practices as the buying and selling of eggs and sperm, abortion for sex-selection and animal-human chimeras. The legislation would also have banned genetic technologies that alter the genetic material that will be inherited by future generations (germ line therapy). The government also proposed a regulatory agency to licence and regulate those involved in genetic technologies. These appear to be positive steps so long as this kind of regulatory agency can include moral oversight as well as technical regulation. Due to the calling of the election in the spring of 1997, this legislation was not passed. We hope the new government will make this legislation a priority.

V. Pastoral Considerations

In general, people seem to respond to individuals with a genetic disease or anomaly with fearfulness, repulsion, uncertainty or even a sense of frustration that the genetic condition cannot be "fixed." But, as Christians, our response to such individuals should be based on the underlying beliefs and attitudes that we hold about the value of a human being. Since all human beings are created in the image of God, they are inherently valuable and must be ministered to in ways that will affirm that value and dignity. Therefore, for Christians, there are no options but to give honour to every life and to respond to all fellow human beings with love and compassion.

"Wholeness" is not of our own doing and could be lost to an accident or disease at any moment--therefore we are who we are by the grace of God and not by merit of anything we have done or have achieved. Remembering this enables us to be with one another humbly, accepting the strengths and weaknesses, abilities and disabilities each of us has. This understanding allows us to engage in mutual relationships which are based on dignity and value, and cultivate hope for today, as well as for the future.

V. Suggestions Regarding Ministering to Individuals with a Genetic Condition

Listen, and learn, but don't offer answers--especially in the initial stages of finding out about the genetic condition. The family will inevitably have to work through the various stages of; so give them time to doubt, cry, question and work out the strong and often extreme emotions they will experience. Don't be judgmental of their expressions of emotion. Pray and cry with them, and "honour" their pain or suffering (physical, emotional and spiritual) by acknowledging that it is valid and worthy of a sympathetic response.

Love─consider how to live out 1 Corinthians 13 in the individual's and/or family's unique situation. Touch is a very powerful expression of love and care and is sometimes more appropriate than a barrage of words: Hold a hand, give a hug or rub a back.

Encourage movement towards hope and meaning in life that is based on the individual's dignity and worth before God and His abundant love for them in the midst of their challenges. Real hope is grounded in a Biblical understanding that God transforms us into the image of Jesus and ultimately brings us into eternal life in Him; while true meaning comes in part from an understanding that faith in God may not mean a "cure," but rather that God's presence will enable us to survive any experience.

Be consistent and regular in your contact with the individual/family. Don't just appear in the crisis, but be committed to be involved for the long haul. Normal daily life, especially in the early stages of adjustment to the "challenge" can be like anyone else's short term crisis. Many people say that they care, but don't want to "bother" families in need by phoning or visiting. However, people only know that others care if they hear from them or see them. Be willing to be with the individual/family on their terms, thus affirming their value and worth. This may require "sacrificial" giving on your part, rather than simply doing what is most convenient for you.

Be creative in acts of kindness. Giving a flower, a card, a plate of cookies or putting all the details in place for a supper out will show the individual/family that you care about them. Find fun things to share with the family, such as movies, games or outings.

Don't wait to be asked to do something. Offer to do household chores, help with care of other children during appointments or hospitalizations or to spend a "night shift" with the individual so that the caregivers can sleep. Become a special person (on a consistent basis) to a sibling of a child with a genetic condition, since these children have their own special struggles and needs.

Don't do for the individual what he/she can do for him or herself. Be patient and allow them the dignity of doing what they can, even if it is a struggle and consumes more time.

Talk about the ups and downs of your own daily life, as well as your own walk of faith. This encourages the individual's family to look beyond themselves and their situation. It also encourages a mutual relationship which gives dignity to the individual.

Include the individual in the events of daily life and offer meaningful involvement in special events. This communicates that the person belongs, is are valued, has dignity and worth, and is cared for.

Volunteer to help find out about the genetic condition as well as the support services that are available so the individual can have as much information as possible to consider his/her situation realistically. The more information that you have will also enable you to make informed and creative decisions about ministering in the situation.

Recognize that these individuals are God's children and the Church has a responsibility to minister to them. While we need services that the government provides, the expression of God's love, compassion and care is a responsibility that belongs to the Church. Churches should be prepared to alter budgets to provide practical assistance to individuals and families in need. Christian families should be similarly prepared to offer financial assistance or to make a commitment to give up a weekly activity so as to have time to give to a specific individual/family.

Medical personnel should be willing to patiently explain the details of the condition many times--it can be a lot to absorb and the emotional adjustment takes time. Don't pretend to know the exact course or duration, but give what parameters are known and be prepared to support people as they adjust to living with the many unknowns of the genetic condition and the factors which influence the condition (such as an individual's own desire to live, develop and overcome challenges; as well as the quality of care they receive, etc.).

VI. Conclusion

The issues relating to genetic research, testing and treatment will not go away.

They have already changed the way physicians treat many illnesses and have created new opportunities for eliminating painful conditions and life-shortening conditions. Researchers anticipate using genetic treatments on many more conditions in the future, such as cancers, cystic fibrosis and heart disease.

At the same time, genetic research, testing and technology can create new evils as well as good. They may foster a value system in which dignity and worth are based on one's genetic makeup, and foster the belief that technological solutions are the only remedy for the human condition. Prenatal testing may lead to pressure for a woman to decide what counts as a "wanted" child. Testing of adults may prejudice their ability to get health and life insurance, or even obtain certain types of employment.

There are many ways Christians can respond to these issues. The most important is to support families with children or dependent adults who are affected by genetically-related disabilities. Christians can also understand and support those who have an emotional reaction to the results of their own genetic tests.

Individuals who have genetic mutations that can cause disability or early death are vulnerable, as are families that have a history of genetically-linked disease. Not only should we care for these individuals on a personal level, but we can also be advocates for them to governments and other bodies that make laws and protocols for how genetic research, testing and technologies are used.

As we face life and death issues in our own lives and the lives of people in our communities, we need to be aware of the Christian principles at stake. New genetic technologies can have an adverse impact on our understanding of the sanctity of life and the sovereignty of God. The temptation to "play God" is very strong--but it must be resisted.

It is only through open and informed discussion that Christians will be able to defend Biblical principles effectively and develop a collective response to each of the issues that result from the use of genetic technology. Canadian churches have an opportunity to lead their members into an understanding of the Biblical principles that are being challenged by some genetic technologies, as well as the ethical, legal and moral issues that arise from their use. In doing so, it is hoped that the Church will be equipped to shed light on these issues and initiate an informed dialogue about them within Canada's communities. There is much at stake and, as the body of Christ, it is our obligation prayerfully and compassionately to develop and model Christian responses to the challenges presented by the use of genetic technology.

VII. Glossary of Terms

BRCA2 (breast cancer susceptibility gene) - a mutated version of the BRCA1 gene, which predisposes a person toward developing breast cancer.

Carrier - a person who has a recessive mutated gene, together with a normal copy of the gene. Carriers do not usually develop the disease but can pass the mutated gene on to their children.

Chromosomes - structures which contain the genes and are found in the nucleus of a cell. Chromosomes come in pairs, and a normal human cell contains 46 chromosomes (arranged in 23 pairs).

Cloning - the process of making genetically identical copies.

DNA - the substance of heredity; a large molecule that carries the genetic information that cells need to replicate and to produce proteins.

Dominant gene - a gene that is expressed, regardless of whether its counterpart gene on the other chromosome is dominant or recessive. Some genetic disorders are produced by a single mutated dominant gene, even though its corresponding gene on the other chromosome may be normal.

Gene - a unit of inheritance; a working subunit of DNA. Each of the body's estimated 100,000 genes contains the code to make a specific product, typically a protein such as an enzyme.

Gene Testing - examining a sample of blood or other body fluid or tissue for biochemical, chromosomal or genetic markers that indicate the presence or absence of genetic disease.

Gene Therapy - treating disease by replacing, manipulating or supplementing nonfunctional genes.

Genetics - the scientific study of heredity: how particular qualities or traits are transmitted from parents to offspring.

Genome - all the genetic material in the chromosomes of a particular organism.

Germ cells - the reproductive cells of the body, either egg or sperm cells.

Germline mutation - a gene change in the body's reproductive cells (egg or sperm) that becomes incorporated in the DNA of every cell in the body of offspring.

Human genome - the full collection of genes needed to produce a human being.

Human Genome Project - an international research effort aimed at identifying and ordering every base in the human genome.

Huntington's disease - an adult-onset disease characterized by progressive mental and physical deterioration caused by an inherited dominant gene mutation.

Mutation - a change in the number, arrangement or molecular sequence of a gene.

Predictive gene tests - tests to identify gene abnormalities that may make a person susceptible to certain diseases or disorders.

Prenatal diagnosis - examining fetal cells taken from the amniotic fluid, the primitive placenta, or the umbilical cord for biochemical, chromosomal or gene alterations.

Recessive gene - a gene that is expressed only when its counterpart gene on the matching chromosome is also recessive (not dominant). Genetic disorders can result in persons who receive two copies of the recessive mutant gene, one from each parent who is a carrier.

Somatic cells - all body cells except the reproductive cells.

Somatic mutations - gene changes that arise within individual cells and accumulate throughout a person's lifetime.

VIII. Suggested Reading

The following is a list of additional reading on this topic. It is not by any means meant to be a comprehensive list, however, it does represent a sampling of the literature that is available for those who wish further information.

Davis, B.D., ed. *The Genetic Revolution - Scientific Prospects and Public Perceptions*. Baltimore, MD:The Johns Hopkins University Press. 1991.

De Vinck, Christopher. *The Power of the Powerless*. Doubleday. 1988.

Gibbard, B., D. Koehn and E. Hui. "Ethical Issues in Genetic Testing and Genetic Counselling." In *Questions of Right and Wrong*, Dr. Edwin Hui, ed. , Vancouver, BC : Regent College.1994.

Kelves, D.J. and L. Hood, eds. *The Code of Codes—Scientific and Social Issues in the Human Genome Project.* Cambridge, MA: Harvard University Press. 1992.

Kilner, J.F., N.M. de S. Cameron, D.L. Schiedermayer, eds. *Bioethics and the Future of Medicine: A Christian Appraisal***.** Grand Rapids: Eerdmans. 1995.

Kilner, J.F., Rebecca D. Pentz, Frank E. Young, eds. *Genetic Ethics: Do the Ends Justify the Genes?* Grand Rapids: Eerdmans. 1997.

Munson, R., ed. Intervention and Reflection*: Basic Issues in Medical Ethics*, 5th ed. Belmont, CA: Wadsworth. 1996.

Nelson, J. Robert. *On the Frontiers of Genetics and Religion*. Eerdmans, 1994.

Noble, David. *A World without Women: the Christian Clerical Culture of Western Science*. Cambridge: Cambridge University Press. 1993

Noble, David. *The Religion of Technology: The Divinity of Man and the Spirit of Invention*. New York: Alfred Knopf. 1997.

O'Donovan, Oliver. *Begotten or Made?* New York: Oxford University Press, 1984.

Reichenbach, Bruce P., Elving Anderson. *On Behalf of God: A Christian Ethic for Biology*. Grand Rapids: Eerdmans. 1995.

Roger, John, ed. Medical Ethics*, Human Choices - A Christian Perspective*. Kitchener, ON: Herald Press. 1988.

Science. Vol 274:465-688, October 25, 1996.

Understanding Gene Testing. NIH Publication No. 96-3905. Bethesda, MD: National Institutes of Health. 1995.

Yancy, Philip. *Where is God When It Hurts?* Grand Rapids: Zondervan. 1990.

IX. Acknowledgements

This paper results from the investigations and work of the Biogenetics Committee, meeting under the authority of the Social Action Commission of the Evangelical Fellowship of Canada. Members of the Steering Committee for this project were: Janet Epp Buckingham, a lawyer and legal analyst (Saskatoon, SK); James E. Read, Executive Director of The Salvation Army Ethics Centre (Winnipeg, MB); Susan Martinuk, a writer and former researcher in the area of infertility and reproductive technologies (Vancouver, BC) and Ab Chudley, MD, a medical geneticist and professor at the University of Manitoba, Faculty of Medicine (Winnipeg, MB). They were assisted in this project by contributions from Dr. Harry Mueller, an obstetrician and gynecologist (Edmonton, AB) and Judy Pope, the mother of a child with a genetic disease and advocate for individuals and families affected by genetic disease (Saskatoon, SK). Acknowledgment is made of the liberal use of the National Institutes of Health document "Understanding Gene Testing" in section II of this paper.