

**A Wonder am I,
and all Your Works
are *Wonders***

Reflections on Some Developments
in the Genetic Technologies



A Sense of Wonder

The earliest records of the Jewish faith, handed on to our age in the Scriptures, express a deep sense of wonder and awe at the miracle of human life. At the end of the first story of creation in the book of Genesis, God is touched by the beauty of all that God had made, the culmination of which is the creation of the human person: “God saw everything that he had made, and indeed, it was very good.” (Genesis 1:31) The Psalmist echoes this same belief in poetry and prayer:

*You created my inmost self,
Knit me together in my mother's womb.
For so many marvels I thank you;
A wonder am I, and all your works are wonders.*
(Psalm 139:13-14)

The sense of wonder about creation that people of faith possess parallels the sense of awe and curiosity that a scientist experiences in a new discovery. The quest for knowledge as well as for wisdom and understanding as a response to wonder lies at the heart of the Catholic faith. Many of the great researchers in the realm of the human sciences have been people of faith; even the founder of the science of genetics, Dom Gregor Mendel, exercised his craft as a response to his faith, as a form of contemplation. Einstein observed: “The most beautiful and profound emotion we can experience is the sensation of the mystical.” Francis Collins, one of the directors of the Human Genome Project, proclaimed that scientific research can be an occasion for worship, offering the fortunate scientist the opportunity to glimpse a new aspect of the beauty of God’s creation.

The rapid progress in the field of genetics invites us to a renewed awareness of the sacred character of the natural order and a deeper sense of gratitude to God, who loves and sustains all creatures. The modern revolution in genetics represents an important new opportunity through which the human community may exercise its call to be stewards of creation in accord with God’s loving intent, seeking always the good of others. As people of faith we may see modern genetic research as a response to the example of Jesus’ healing ministry and a way to promote a culture of life. The Church rightly supports the search for knowledge if it respects the dignity of human life, the sacred character of the entire natural order and the limits of human understanding and control.

We hope that the information and reflections in this booklet will increase awareness within the Catholic community about both the marvels and the challenges associated with the new genetic technologies.



The Human Genome Project

1. The language in which God created life

The Human Genome Project, which seeks to uncover and catalogue the genetic makeup of the human species, exemplifies the link between the wonder of science and the marvel of God's creation. In announcing the publication of a first draft of the human genome* in February 2001, politicians and scientists from around the world spoke of the language of genetics as the language in which God created life. Thus, in a sense, the whole world sees the Human Genome Project as one of the great scientific achievements of human history.

The Human Genome Project invites us to consider the following:

- *the diversity and beauty of the human person*
- *the marvel of our genetic makeup, which plays such an amazing role in shaping us*
- *the shared genetic heritage of all forms of life, which inspires us to consider our relationship to the rest of the natural order*
- *the ordered character of nature amid what can seem random.*

These discoveries can move Christians to desire even deeper knowledge, to thank God for the wonder of creation, and to recognize scientists for the fruits of their labour.

The information gathered through the Human Genome Project will improve our understanding of the genetic basis of human health and illness and will help scientists develop better treatments for many human diseases. Such knowledge can reveal in new ways the providence of God. Indeed, believers will continue to find in the scientific community men and women who view their work as a meditation on God's action in the world and as a response to the call to be stewards and healers.

* "Genome" refers to the total genetic makeup of a particular organism.



2. We are more than our genes

The fast pace of modern society, with its increasing reliance on technological advancement, has sometimes meant the loss of a sense of awe before creation. Some people think that knowing how things work means knowing their ultimate meaning. The great knowledge gained through the Human Genome Project about important biological features of our human nature may lead some to think that such knowledge provides the final answer to all human questions, as if “we are only our genes.”

How do we know that we are more than our genes? Biology itself provides one answer. As with all matter, living or inanimate, our genes consist of atoms. When individual atoms unite to form molecules, new properties result. Similarly, when complex molecules join to form the membrane of a cell or a strand of DNA, new properties appear. These new properties are more than the sum of the properties of each molecule. The same is true when cells differentiate, growing into tissues and organs. They form integrated systems of organs that make possible the physical and mental life of an individual. As the biological point of view shows, we are more than the sum of our atoms or genes.

Scientists who meditate daily on the wonders of the natural order also call us to avoid having a simplistic understanding of human genetics. Our physical characteristics are the result of the complex interaction of many thousands of genes and their products

with an equally complex assortment of developmental and environmental factors. While we try to understand the part genetics plays in human diseases and even human behaviour, we must also continue our research in the other human sciences. These areas of study seek to shed light on the complex physical and social web of human interactions. Such a broad view of the human condition is necessary if we are to avoid a reductionistic and determinist view of the role of genetics in human life, health and disease.


Though we may marvel at the progress of modern science, the latest information from the field of genetics also challenges us to pause and reflect on the implications of new discoveries. These discoveries affect our understanding of human dignity, freedom and responsibility, and the integrity of the natural world. People of faith believe that humankind is created in the image and likeness of God; this belief relates to our physical bodies, but goes far beyond them. Our sacred nature entails so much more than can be grasped or imagined by the study of our bodies. As people of faith, we need to challenge any perspective that loses sight of the sense of wonder and awe that is rooted in the gift of our relationship with God and the rest of the human community. Believers participate in God’s care for the world by being loving and responsible towards the larger community and by helping to shape the future.



3. Limits and Possibilities

Information about the human genome is an extraordinary resource that can lead to great knowledge and great potential good. Yet, it may lead us to forget that creation – and its Creator – is far greater than we are. We may move from a stance of co-operation and co-creativity, as Pope John Paul II put it, to a desire for mastery or domination, even of the human person. Whenever knowledge crosses that frontier, the Christian tradition has legitimate concerns that such a narrow focus loses a sense of limit and proportion and may harm the human person, the human race, and the world as a whole. Considering the powers and limitations of modern genetics, scientists warn that we must respect the ways genes have evolved: not as isolated entities, but in concert with the rest of the genetic characteristics of an organism.

Though scientific efforts such as the Human Genome Project provide important new insights into human genetics, we have much to learn about how genes are activated or silenced and how environmental factors influence human development and health. As modern science continues to provide new possibilities for manipulating the genetic material of a wide range of species, we must discover how this new technology may be used to promote the health and dignity of the human community and, indeed, of the natural order, on which all of life depends. Results of the genetic analysis of organisms from throughout the various realms of the natural order remind us of the profound relationship that exists between all forms of life. Our religious traditions reinforce that respect and care for life must accompany these new insights and future scientific discoveries and applications.



The Human Genome Project is an international scientific effort to decode and catalogue the basic genetic makeup of the human race. Because all human diseases are influenced by our genetic makeup, there has been a strong commitment to and a large investment of financial and human resources in the mapping and decoding of the human genome.

Highlights:

- Since each cell in the human body is derived from the original products of fertilization, each cell contains the entire human genome: that is, all the genetic information needed to build a human being.
- Genetic information is organized into functional units known as genes. Genes are scattered along the coiled strands of DNA (deoxyribonucleic acid), known as chromosomes.
- Genes may carry information for the production of proteins, the workhorses of the body.
- Current estimates suggest that the human genome contains between 30,000 to 40,000 genes. In comparison, the nematode worm contains 18,000 genes and the fruit fly contains 13,000 genes.
- The Human Genome Project helps to remind us that all members of the human community are related: each individual shares 99.9 % of the same genetic code with every other human being.

Things to Keep in Mind:

- Despite the successes of the Human Genome Project, scientists caution that genes tell only a tiny part of the story of our biological makeup.

Potential:

- Information gained from the Human Genome Project holds great promise for the early diagnosis of diseases, the production of new vaccines and drugs, and the development of some forms of gene therapy.

Concerns:

- Who owns the genetic information relating to the human species?
- Will people be misled into believing that this new genetic knowledge will be the answer to all health concerns?
- A person is much more than their genes or their biology; we belong to communities, live in relationships, work and are creative.
- The possibility of knowing and manipulating the hereditary characteristics of an individual raises serious legal, social and ethical questions.



Human Genetic Testing

1. The Promise of Genetic Testing

The possibility of human genetic testing, especially among families or communities with a history of certain diseases, offers great opportunities. It can be an important diagnostic tool aimed at improving medical care. In some cases, it can confirm a diagnosis or reveal an increased likelihood that individuals or extended families may face particular medical problems in their future. It may also help to lessen people's fears about transmitting inherited diseases or provide useful information to help people prepare to deal with such diseases and the stress that may accompany them. Moreover, the knowledge gained from genetic testing can help to open the door to further scientific research and improvements in medical care.

But genetic testing offers challenges as well. As it becomes a more common feature of our medical practice, we must take care that, like other medical treatments, these tests are optional. No one should be coerced into being tested. The fact remains that many tests are difficult to interpret, offering little positive information that could be used to determine a therapeutic course of action. Under such circumstances it seems reasonable that some people would simply prefer not to know. This is often the case with certain forms of prenatal diagnosis where no immediate therapy can be offered and parents are ready to welcome the child even if he or she has a serious disease or handicap.

Couples who choose to undergo genetic testing if it is recommended to them may gain a fuller sense of their child's special needs before the birth and prepare themselves accordingly. Families may benefit from a fuller sense of their genetic heritage and of the conditions for which they might be at a higher risk. All involved must recognize, however, that no one gene dictates the future. Given the complexity of the knowledge involved, persons who wish to undergo genetic testing should seek out expert counsellors who can help them understand the results of these tests and can support them as they try to develop an appropriate response to this information. Such guidance would engage a process of ethical reflection and decision-making in addition to the basic analysis of the medical information. The most powerful guide, however, will often be found in the experience of loving individuals and communities that have cared for people who have serious diseases. Insofar as genetic testing helps people to prepare for the future and to meet the challenges of our genetic endowment, it represents a great asset to humanity.



2. Concerns About Genetic Testing

Genetic discrimination

As we enter this new age of genetic medicine, the lessons of medical and political history provide a cautionary tale. During much of the nineteenth and twentieth centuries, many nations promoted policies of ethnic discrimination and apartheid based on an assumption of “racial” or national superiority. The discipline of eugenics or “good breeding” was used to support racist immigration policies and to justify the forced sterilization of people deemed to be genetically inferior.

Genetic testing may be performed on adults to determine their predisposition for developing particular diseases and conditions themselves and which may be passed on to their children. Genetic testing may also be done prenatally, either prior to implantation on human embryos created through IVF or during the pregnancy itself.

In preimplantation diagnosis, embryonic humans are examined and then transferred to a uterus only after the presence or absence of particular attributes has been determined. More commonly, pre-birth genetic testing occurs once the pregnancy has been established. Various types of prenatal diagnostic tests provide information about the fetal human that may help parents to prepare for the birth and care of a child with a disability. However, prenatal diagnosis is more often than not followed by selective termination of pregnancy (also known as a genetic or eugenic abortion) when a fetal anomaly is detected.

While all parents hope to have a “healthy” baby, prenatal diagnosis, when followed by selective abortion, becomes a form of eugenics, preventing the birth of babies with anomalies. Preimplantation diagnosis takes this further, allowing parents to have “designer babies”, chosen for particular characteristics. In both prenatal and preimplantation diagnosis, there is the danger of objectifying — even commodifying — unborn children by subjecting them to a form of quality control and, if they are found lacking, not bringing them to birth. Within this context of extreme pragmatism, quality of life based on the parents’ desires determines the fate of the unborn children.

Information gained through modern genetics calls us to repudiate the evils of the past, when pseudo-scientific ideas were used to support oppressive social policies. Data gathered from the Human Genome Project support the view that in the eyes of nature, as well as in the eyes of God, we are one human community with a common origin and a common destiny. The Church strongly rejects any discrimination arising from genetic testing; those at higher risk for genetically based conditions fully remain our sisters and brothers. Whether born or not-yet-born, those actually suffering from anomalies or disabilities are nevertheless made in the image and likeness of God who loved them into existence.

Genetically normal


Today’s culture may view the suffering person as simply a burden, perhaps even a burden to be terminated. Genetic testing



must always guard against the tendency to accept only those persons who are judged to be “normal” and who impose no “burden” on society. Modern genetics highlights the folly of any program aimed at eliminating all genetically based predispositions to human disease. The partially random character of our biological inheritance dictates that disease resistance and susceptibility is a constantly changing feature of our human constitution. Everyone is at risk of developing a wide range of diseases; only some of these genetically based risk factors will contribute to the development of a recognizable disease. Furthermore, the meaning that emerges from this experience of illness or disease will depend upon our individual and communal understanding of the human journey. Our society’s response to disease will show itself in the types of health care systems we adopt and in the laws we devise to guard against different forms of genetic discrimination.

Genetic privacy

Genetic testing requires free and informed consent, and individuals and families who seek genetics services require counselling. The knowledge gained from such tests always remains the “property” of the persons tested. The dignity of the human person includes his or her genetic code as well as any samples or tissues provided for examination; any further use of such samples or tissues also requires free and informed consent. Each person is entitled to his or her own human genome. Genetic data should not be used to restrict a person’s access to social goods, such as health insurance or employment.



Genetic Testing can be carried out on adults or on babies in the womb (Prenatal genetic diagnosis – PGD). Such testing can identify whether a person

- is a carrier of a particular genetic trait
- has a genetic trait associated with a disease or a predisposition for a disease that might show up later in life, such as Huntington’s disease or breast cancer.

Things to Keep in Mind:

- Although we can identify a multitude of genetic abnormalities and diseases associated with them, the precise health implications of these conditions often remain difficult to predict. Genetic information can suggest an increased or decreased risk for certain conditions, but the precise impact of a particular genetic variation may be known only with time.
- Even if we know that a particular genetic variation is associated with a disease state, we cannot always cure the disease.
- Genetic tests that are available now cover only a limited range of conditions.

Potential:

- Testing can provide for the early introduction of treatment.
- The information derived from testing can help people prepare for possible illness or disease in themselves or in a child.

Concerns:

- Prenatal diagnosis often leads to the abortion of children with disabilities.
- Will testing lead to the promotion of some genetic traits as more desirable than others? In the concern to improve the human condition, is there not the risk of a new and more subtle form of eugenics? Should the right to be born or to live belong only to those with certain qualities?
- Insurance companies and employers could use genetic information to weed out “high-risk” clients or employees.
- Raises issues of privacy and confidentiality of information.
- Has social implications. Can one member of a family be tested without the issue being forced on others? People have the right not to know.

1. A Ray of Hope

We are all filled with compassion for those who suffer from very serious medical or emotional illnesses. The possibility of some form of therapy to help these people can seem very appealing; indeed, many people search the news media or the web for the latest information on possible treatments to help themselves or their loved ones.

The knowledge gained from the science of genetics, especially from the mapping of the human genome, offers many glimpses of such possible treatments. The media reports a constantly growing list of new discoveries and potential benefits from the field of genetics. For example, we now know of genes linked to a greatly increased risk of breast cancer in some families, and of other genes that play a key role in cystic fibrosis and muscular dystrophy. Genes involved in disorders of the blood and immune system as well as certain degenerative conditions of the nervous system, have also been identified. At times, it seems we are only a small step away from being able to identify, treat or offer cures to persons suffering from such afflictions. Medical researchers have also gained a better understanding of the genetic characteristics of disease-causing agents associated with such major diseases as AIDS, tuberculosis and malaria. Through

these studies, medical science seeks to lessen the enormous burden that these diseases impose on individuals and nations.

Although the media likes to highlight new genetic discoveries, it sometimes fails to demonstrate the complexity surrounding these issues. The media may give the impression that each human disease is caused by a particular gene that could be fixed through gene therapy providing lasting relief for individuals carrying these genes. The reality of human genetics, disease susceptibility and the possibility of genetic therapies is usually much more complex. While genes may play a significant role in many illnesses, both physical and psychological, most human disease will not show a simple one-to-one cause-and-effect relationship to a particular dominant genetic trait. A whole host of issues comes into play. Also, while the new knowledge opens exciting horizons for eventual treatments, there have been few concrete results from experiments that are currently underway. Still, the promise of new treatments and new cures (new drugs, vaccines and even some forms of gene therapy) should not be dismissed; for many people, such developments provide a ray of hope in an otherwise dark situation.



2. Some Cautions

Those who are thinking of participating in these experimental therapies should seek out as much information and guidance as possible before making a decision. The benefits and the risks of such trials are both substantial. A process of ethical reflection and decision-making can help the persons involved achieve a truly **informed consent**.

People must recognize the *limits of human action*. Often, people are driven to seek almost any option for extending life, even if it comes at a very high price. Unrealistic expectations of the power of medical science can lead to risky decisions and the seeking of cures at any cost.

As with all learning, it is important to clarify *whose interests* are being served in these new gene-therapy regimes. Therapies must aim primarily at helping persons, not simply at increasing knowledge, prestige or profits.

One particular form of gene therapy raises significant concerns: *germ-line therapies*. It is possible that one could act to repair a problem gene by treating human eggs and sperm or by a therapeutic intervention on the cells that give rise to these cells. Such therapy would affect not only one person but all of that person's descendants. Since these germ-line changes cannot easily be undone, and because all the consequences of these interventions cannot be predicted, most ethical bodies today demand that researchers refrain from such therapies. This seems to be a wise limitation and a prudent course of action.



Gene therapy attempts to treat, cure and even prevent the development of disease by altering particular genes. Presently two experimental forms of gene therapy are being considered:

- **Somatic gene therapy** seeks to treat or cure the person's disease. Such therapies may be accomplished in two ways:
 - by removing cells from the body, correcting them by genetic manipulation and replacing them, or
 - by introducing new genes directly into the site of the disease.
- **Germ-line therapy** aims to remedy a genetic problem by correcting genes in the germ-cell populations of prospective parents or by altering all or most of the cells of a developing embryo. In both cases this genetic therapy would correct the individual's condition and ensure that the correction was passed down to his or her descendants.

Things to Keep in Mind:

- Gene therapy is a highly experimental and costly procedure.
- The relationship of genetic traits in a human person is extremely complex. It involves a network of different genetically determined characteristics and environmental influences interacting through a complicated developmental pattern.

Potential:

- Being able to treat, cure or prevent diseases from a very early stage of the disease.

Concerns:

- Does anyone have the right to modify the genetic makeup of future generations?
- It is not only our genes that determine human traits; environmental factors including the social, emotional and nutritional circumstances all play a role.
- The likely association of germ-line therapy with cloning technologies.

God's Delight and Challenge

The Genesis account of creation speaks of God's relationship with the created order and God's delight in what had come into being, but it also speaks of the challenge that God places before humanity. The Catholic tradition recognizes that knowledge should lead not only to gratitude and wonder, but also to the development of a form of wisdom that is permeated by love and promotes a sense of responsibility for the world. The stewardship that God has entrusted to us is a way of being faithful to God, the Creator. This calls for us to act in the pattern of God's own act, responding in wisdom and love to the challenges we face. Our experience of God, engaged with the natural order, directs us to respect the diversity and richness of the creation and, in a particular way, to value the dignity of the human person, who is made in God's image and likeness. God created us as members of a family with roots in a larger community; we are social beings and cannot live outside the web of human relationships. Respect for human dignity and the values of the common good within the context of the beauty of creation are at the heart of all Catholic teaching.

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COLF was jointly founded by the Canadian Conference of Catholic Bishops and the Knights of Columbus to promote respect for human life and dignity and the essential role of the family.

CHAC is a national Christian association committed to health care in the tradition of the Catholic Church. It represents health care and social service organizations, including 127 hospitals and homes, as well as health professionals involved at all levels of health care throughout the country.

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