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Human dignity and genetic
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HUMAN DIGNITY AND GENETIC HERITAGE

Protection of Life Series

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Protection of Life Series

A Study Paper prepared for the

Law Reform Commission of Canada

by

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Introduction

The advent of the year 2000, and of the next millennium, portends tremendous promise in the science of human genetics. Like the discovery of the atom and, more recently, the ability to conceive human life *in vitro*, advances in human genetics harbour the potential for good and for evil. The very essence of humankind is at stake. At the same time, the potential of this science lies in the knowledge it provides, knowledge that will finally force to the forefront a discussion of the nature, uniqueness and potential for change of the human species. Indeed, the era of genetics will provide us with the opportunity and the duty to give meaning to the inherent dignity of the human person.¹

The lack of precise knowledge about where human genetics might take us raises false hopes in some and leads others to make wholesale denunciations. The latter group has applied such terms as "interfering with nature," "playing God" and the "slippery slope" to genetic engineering.² There is no doubt that the new tools of human genetics do, and will, affect the human being in the ultimate substratum, namely, the gene. Whether the result will be "good" or "evil" will depend on whether individuals, scientists and governments seek and apply genetic knowledge responsibly and discriminately. In order to understand the potential of this knowledge, we must understand first how the progress in molecular genetics has changed the practice of medical genetics (Chapter One).

In 1982, the Council of Europe, in its recommendation on Genetic Engineering, advocated that the right to life and to human dignity implied the right to an unaltered genetic pattern – one that had not been artificially altered.³ It also proposed that this right should be made explicit in the European *Convention for the Protection of Human Rights and Fundamental Freedoms*.⁴ However, no guidance was provided as to what was meant by a genetic pattern or heritage or how it could be protected from change by means of law.

1. *Universal Declaration of Human Rights*, G.A. Res. 217/A, Off. Doc. G.A., 3rd Session at 71, U.N. Doc. A/810 (1948):

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world . . .

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women . . . (Preamble).

2. Keith Boone, "Bad Axioms in Genetic Engineering" (1988) 18:4 *Hast. Cent. Rep.* 9.

3. Council of Europe, P.A., 33rd Sess., Pt III, *Texts Adopted, Recommendation 934 (1982) on Genetic Engineering*, s. 4(i).

4. (1955) 213 U.N.T.S. 221 [hereinafter *European Convention on Human Rights*].

Considering the advances in molecular biology affecting human genetics since that 1982 recommendation, we must now determine what genetic heritage is. Does it mean the collective gene pool or the individual genome?⁵ Answers to this question are necessary to decide what is inherent to human dignity that merits legal protection (Chapter Two).

Even though the inherent dignity of the human person is seen as fundamental, its interpretation in a human rights context is not yet clear. However, there is no doubt that respect for the human body, for one's genetic make-up and origins, is indivisible from respect for the person. Human cells, with their genetic information, are more than a temporary substrate for the existence of the human body; they are a constituent of human dignity. The Council of Europe linked the right to protection of the genetic heritage to the right to life and to human dignity. However, it did not exclude therapeutic interventions. In fact, its preliminary report contains the startling suggestion that reproductive freedom of those persons at risk of transmitting certain serious genetic illnesses might be linked to their consenting to genetic therapy to reduce the probability of transmitting those illnesses to subsequent generations. Thus, assigning a right to a "healthy" genetic heritage to protect human dignity may do as much to undermine that human dignity by restricting freedom (Chapter Three).

While the meaning of human dignity in international human rights law is not fully developed, the notion can serve as the foundation for the interpretation of human rights in the context of constitutional law. In particular, under the *Canadian Charter of Rights and Freedoms*, the rights to life, liberty and security of the person, the right to be free from unreasonable search and seizure and the right to equality and protection from discrimination have been seen as based on the recognition of that inherent dignity.⁶ We may then ask whether such constitutional guarantees are directly applicable to the issues raised by the new human genetics in a free and democratic society such as Canada. Some examples of issues that may arise are: compulsory testing for disease or carrier status in particular groups of individuals; the obligation of parents to have their children tested for treatable diseases; and the use of DNA samples for unauthorized purposes (Chapter Four).

Improving the capability to treat or alter the genome of an individual and genetic testing to identify the risk of future diseases may result in stigmatization. Indeed, "[f]rom a societal perspective, a gene probe for manic depression may be seen as akin to AIDS antibody testing: in both instances, testing leads to the uncovering of a marker."⁷ The marker could predict (with varying degrees of accuracy) the onset of the disease. But attached to this prediction is a substantial risk of social stigmatization.

5. See the Glossary, *infra* at 77 for the definitions of technical terms.

6. Part I of the *Constitution Act, 1982*, being Schedule B of the *Canada Act 1982* (U.K.), 1982, c. 11, ss. 7, 8 and 15.

7. Marc Lappé, "The Limits of Genetic Inquiry" (1987) 17:4 *Hast. Cent. Rep.* 5 at 7.

Such stigmatization and our reactions to the new genetics may be shaped by our view of human nature. If one sees genetic consequences as inevitable and certain, one may be inclined to look to the elimination of the genetically disabled rather than to the finding of ways to accommodate such persons within society. By adopting this view we are deciding what is "normal" and acceptable. We may, for example, screen workers and exclude them on the basis of their susceptibility genes, rather than looking to reduce the risk of disease by cleaning up the workplace. We may fail to examine our political system, which leaves those with genetic disabilities less insured than those without. We may exert pressure on individuals to control their reproductive outcome according to our view of normality, and promote the elimination of the handicapped by abortion rather than making the world a better place for them. If, on the other hand, we see the diversity of our genetic constitution as natural and as the essence of humanity, we may resist genetic intervention regardless of its moral justification (Chapter Five).

Three ethical principles may be considered in an evaluation of the impact of modern science on the human being: autonomy, beneficence and non-maleficence. In the context of modern molecular biology and predictive genetics, as in medicine generally, the principle of autonomy may conflict with the principles of beneficence and non-maleficence. What framework do these principles provide for future legislative policy?

On a governmental level, the use of a cost-benefit analysis with its utilitarian rationale could lead to considerable pressure to test or be tested. It could force individuals to know about their genetic predispositions, to tell others and to act, so that the "proper choices" of those individuals would save society the long-term costs of disabling diseases. Such economic incentives could lead to a new eugenics based, not on undesirable characteristics, but rather on cost-saving, a form of economic social justice rather than "genetic justice." Considering those choices, genetic justice will require both greater communication of knowledge within the protection of the physician-patient relationship and civic responsibility on the part of the participant to share knowledge that will benefit his or her family (Chapter Six).

The development of a theory of genetic justice will require an in-depth examination of human rights in the workplace, in matters of insurability and in the physician-patient relationship. Other issues that will need full elaboration in the future are: the individual's control of bodily tissues or cells and of the genetic information contained therein; control of the diffusion of genetic information to family members; and the availability and adequacy of genetic counselling services and genetic education.⁸ However, the values and policy issues underlying such specific subjects require delineation now.

8. See generally Neil A. Holtzman, *Proceed with Caution: Predicting Genetic Risks in the Recombinant DNA Era* (Baltimore: Johns Hopkins University Press, 1989); Lori B. Andrews, *Medical Genetics: A Legal Frontier* (Chicago: American Bar Foundation, 1987).

This study attempts to establish the basic, yet changing, philosophical and scientific knowledge underlying new developments in the science of human genetics. It looks at the impact that this understanding will have on the definition and legal protection of the human genetic heritage. The concept of genetic heritage and the legal means to protect it must be situated within an analysis of what is meant by the inherent dignity of the person. This will allow us to envisage a revised concept of genetic "abnormality" within a new concept of genetic justice.

The new genetics affects us individually and collectively, in our social, political and economic fabric. However, the inherent dignity of the human person, as recognized in the international covenants and national constitutions, has not yet been fully interpreted by the courts. It will be argued that the recognition of the dignity of each person, and of humanity as a whole, requires an approach to the protection of our genetic heritage that is based on medically oriented principles of respect for human life. It will be shown that human life in the genetic sense is not fixed in time, nor can it be reduced to one immutable gene pool. This study proposes that respect for the complexity, variability and uniqueness of the human being, and the recognition of equality through genetic difference, may be accomplished through the widespread genetic education of both the public and the medical profession. The failure to so educate could lead to the misuse of genetic knowledge for discriminatory purposes. It could also lead to the dangerous language of "genetic rights" with its accompanying legal claims and obligations. In short, the purpose of this study is to attach some meaning to the inherent human dignity of the person in the context of the new choices of human genetics, and to propose interpretations of human dignity that ensure the indivisible genetic nature of the human person within a common social ethic, that of genetic justice.

CHAPTER ONE

Genetics Overview

I. Introduction

Humankind has had an intuitive understanding of the inheritance of physical characteristics for thousands of years. Farmers have, over the centuries, improved the characteristics of domestic animals and crops by selecting those with superior characteristics for breeding purposes. But it was only a little more than a century ago that the biological basis of inheritance began to come to light with the work of the Austrian monk, Gregor Mendel. He was able to establish that there are units of inheritance that are transmitted from generation to generation, according to simple mathematical rules. In other words, genetic heritage can be predicted.

The early part of the twentieth century saw an explosion of genetic research that elaborated on Mendel's work. First, it was established that the units of inheritance described by Mendel are carried on the chromosomes. In the 1940s the composition of the hereditary material was discovered. This substance, called deoxyribonucleic acid (DNA), carries the genetic information of every cell. The next step was to discover how this information could be passed on from one cell to another. In 1953, James Watson and Francis Crick discovered that the DNA is arranged in a way that accomplishes this — in the famous double helix. That discovery won them the Nobel prize.

Since then, human genetics has been revolutionized by advances in what is called molecular biology.⁹ Some of those technological advances will be described. But first we summarize how our genetic differences arise, and what kinds of differences lead to changes in the appearance or function of the human organism. Next is an examination of how advances in molecular biology have changed the practice of clinical genetics.

9. Claude Laberge, "La révolution biologique" in Jacques Dufresne, Fernand Dumont and Yves Martin, eds, *Traité d'anthropologie médicale* (Québec: Presses de l'Université du Québec, 1985) at 201.

II. The Structural Basis of Genetic Differences¹⁰

Inherited characteristics are transmitted by genes. The genes are arranged on thread-like chromosomes. Twenty-three pairs of chromosomes are found in each of the body's cells.¹¹ One chromosome of each pair comes from the mother via the egg, and the other comes from the father via the sperm. The egg and the sperm (also called germ cells or gametes) are formed in the ovaries of the female and the testes of the male, respectively, by a process called meiosis. During meiosis the pairs of chromosomes become aligned side by side. There is a crossing over of genetic information between the pairs. Then the pairs separate. The result is that the germ cells have 23 chromosomes each instead of 23 pairs, and each germ cell bears a mixture of genetic material from the parental chromosomes.

Germ cells contain 22 autosomal chromosomes. These are the chromosomes found in both sexes. There is also a sex chromosome in each germ cell. In the egg it is always an X-chromosome, and in the sperm it can be an X- or a Y-chromosome. Union of the egg with an X-bearing sperm results in a female, and with a Y-bearing sperm, a male. After this union — the fertilization — cell division gives rise to the body cells called somatic cells which, as we have said, have two sets of chromosomes.

The unit of inheritance is the gene and the chemical composition of the gene is the DNA, which consists of two strands wrapped into a double helix. The strands are linked together by bases or nucleotides¹² as in the rungs of a twisted rope ladder. This structure is the double helix.

The sequence of bases in each strand can be deduced from that of the other. This complementarity between the two strands of DNA is the key to its information-bearing capabilities. The sequence of nucleotides in the gene is transcribed into a messenger molecule: messenger ribonucleic acid (mRNA). The mRNA moves from the nucleus of the cell out into its cytoplasm. Here, the sequence of nucleotides in the mRNA serves as a template to assemble amino acids into the protein. Thus, the DNA determines the sequence of mRNA bases, which determines the sequence of amino acids, which in turn determines the structure of the protein. That is, every protein has a specific gene that determines its structure.

However, not all of the DNA in the nucleus codes for proteins. A significant amount of the remaining DNA is dispersed within or between the protein-producing

10. Holtzman, *supra*, note 8.

11. Except for the sperm and the egg, which have 23 unpaired chromosomes each.

12. There are four types of nucleotides in DNA: adenosine (A), guanosine (G), cytidine (C) and thymine (T). Adenosine will only link with thymine and guanosine with cytidine. The nucleotides in the messenger ribonucleic acid (mRNA) are complementary to the DNA except that RNA contains uracil (U) instead of thymine.

genes. Some of this non-coding DNA is involved in regulating the activity of the genes. In others, the function of non-coding DNA is unknown.¹³

The complete set of genes of an individual is its genome. A gene is located at a particular locus on one of the chromosomes. Each of us has two genes at each locus, one on each paired chromosome (except in the male, where the sex chromosomes are XY).

The pair of genes at a particular locus may be identical or they may differ in the information they carry. Different forms of genes are called alleles. Alleles arise from a spontaneous change (called a mutation) in the DNA which, in the simplest situation, is a change in a single nucleotide pair. This may result in a different amino acid in the protein. When a mutation occurs in a germ cell, the change may be transmitted to the offspring and in turn to future generations. Mutations provide for genetic variation in a species, and this allows for evolution. Through evolution, the most advantageous allele will be selected. Some mutations appear to be neutral — that is, they do not seem to be more or less advantageous than others. Neutral genes may have several alleles at a given locus, none of which is rare. These kinds of alleles are called polymorphic. Polymorphisms also occur in the DNA between genes and, as we will see, constitute an important tool in mapping the genome.

Although some mutations are advantageous to the organism, and some are neutral, most will be deleterious. It is the deleterious genes which may result in disease or dysfunction.

III. Genetic Disorders

It is estimated that at least one in ten Canadians will die, or be impaired, disabled or handicapped at some time in their lives, as a result of deleterious genes. Diseases with a genetic component account for 30 to 50 per cent of admissions to paediatric hospitals.¹⁴ Yet our understanding of the pathogenesis of these disorders and their treatment is limited, and the gene locus is known in only 3 per cent of them.¹⁵

Genetic disorders can be divided into three categories: chromosomal, single gene and multifactorial.¹⁶

13. See Arno G. Motulsky, "Medical Genetics" (1989) 261:19 JAMA 2855.

14. See generally, Government of Canada, *A New Perspective on the Health of Canadians* (Lalonde report) (Ottawa, 1974). See also the contrasting figures in Alan E.H. Emery and David L. Rimoin, "Nature and Incidence of Genetic Disease" in Alan E.H. Emery and David L. Rimoin, eds, *Principles and Practice of Medical Genetics*, vol. 1 (Edinburgh: Churchill Livingstone, 1983) at 1-3.

15. National Research Council, *Mapping and Sequencing the Human Genome* (Washington, D.C.: National Academy Press, 1988) at 28.

16. See James J. Nora and F. Clarke Fraser, *Medical Genetics: Principles and Practice*, 3d ed. (Philadelphia: Lea & Febiger, 1989) for a more detailed discussion of genetic disorders.

A. Chromosomal Disorders

In 1959 it was discovered that children with Down syndrome have 47 instead of the normal 46 chromosomes (trisomy 21). Soon after, other disorders were found to be associated with too much or too little chromosome material. In the 1970s, new histological staining techniques improved the ability to study chromosomes under the microscope, and brought to light even more chromosomal disorders.

The absence or excess of chromosomal material may involve all or part of a whole chromosome. Most disorders arise from errors in the separation of the chromosomes at meiosis. Chromosomal disorders occur in about one of 200 live-born individuals. Most of those people are mentally and physically disordered, and are often malformed.

Chromosome disorders can be detected prenatally. Testing is generally offered where a woman is 35 years of age or older,¹⁷ a couple has had a previous child with a chromosomal disorder or one member of a couple is known to have a balanced chromosomal rearrangement.

B. Single Gene Disorders

The second category of genetic disorders is often referred to as Mendelian because their inheritance follows the rules of inheritance established by Gregor Mendel. We now know of more than 4,000 Mendelian traits of which about 3,000 may cause disease or dysfunction.¹⁸ If the disorder is expressed when only one of a pair of alleles is defective, it is said to be dominant. Such disorders may be expressed to differing degrees in different people (variable expressivity). In some individuals, the disease may not be expressed at all (reduced penetrance). These phenomena, and the fact that a disorder may not appear until late in life, make it difficult to predict the severity and age of onset of the disorder in a particular individual.

Where both alleles must be defective for the disorder to be expressed, it is said to be recessive. The parents, who each carry the mutant allele, may be outwardly normal. With some recessive disorders it is possible to detect carriers (for example, for sickle cell anaemia), making it possible to identify who in a population carries the gene. Where it is not possible to detect carriers, parents only know that they are carrying the defective allele after the mother gives birth to an affected child.

For some genetic disorders, the consequences of the abnormal gene may be prevented by environmental manipulation. For example, in phenylketonuria (PKU), the defective gene results in a defective enzyme that would normally convert phenylalanine

17. There is an increasing risk that a woman will have a child with Down syndrome the older she is.

18. Victor A. McKusick, *Mendelian Inheritance in Man: Catalogs of Autosomal Dominant, Autosomal Recessive and X-linked Phenotypes*, 9th ed. (Baltimore: Johns Hopkins University Press, 1990).

to tyrosine. The resulting accumulation of phenylalanine causes a mental disorder. However, this accumulation can be prevented if the dietary intake of phenylalanine is carefully controlled from the newborn period and at least throughout early childhood, and in this way the long-term effects of PKU can be minimized.

The last type of single gene disorder is the so-called X-linked recessive disorder. Like autosomal recessive disorders, this type is not expressed when there is a normal allele on the other chromosome. Thus, a female with only one defective X-chromosome will be normal. However, if her son inherits the defective X-chromosome, as in haemophilia, he will have the disorder because he has no second X-chromosome to protect him.

There are over 50 single gene disorders that are detectable prenatally, by the use of biochemical tests on foetal cells obtained from the pregnant woman's amniotic fluid.

C. Multifactorial Disorders

The final category of genetic disorders to be discussed consists of multifactorial disorders. It is somewhat arbitrary to classify them as genetic since environmental factors may be as important as the defective genes in their causation and expression.

Multifactorial disorders include common diseases such as hypertension, coronary heart disease, atherosclerosis and diabetes and common birth defects such as spina bifida. A genetic component may be deduced from family studies, as in spina bifida. In other cases, a gene may have been identified that increases susceptibility to a disorder.¹⁹ Most common genetic disorders are complex and heterogeneous. A disease or malformation may have a different set of causal factors in different families or in different individuals.

IV. Technological Advances in Molecular Biology

The importance of the technological advances in molecular biology relates to their use in mapping the human genome. Mapping means finding the position of the gene that causes a genetic disorder on a particular chromosome, and finding its position in relation to other, adjacent genes.

19. Lappé, *supra*, note 7 at 10. *E.g.*, ankylosing spondylitis (spinal fusion) is associated with the B-27 allele at the gene locus for human leucocyte antigen (HLA). However, not all individuals with the susceptibility gene will develop the disorder, while some individuals without the gene will.

A project to determine the sequence of the entire genome, approved by the United States Congress,²⁰ has expanded into an international collaborative project (HUGO).²¹ It will provide information that could lead to the avoidance or prevention of genetic disorders and eventually to their treatment and even cure.²² The following discussion highlights some of the technological advances that have made that project feasible.²³

A major advance in mapping came in the 1980s with the use of "restriction fragment length polymorphisms" (RFLPs). Restriction enzymes, of which there are hundreds now known, cut the DNA into fragments at both ends of specific nucleotide sequences. The length of the fragments is specific for each enzyme. If a mutation occurs at a particular cutting site, the enzyme will not cut the DNA at that site, and the length of the resulting DNA fragment will change. Thus, when the particular fragment is labelled with a probe, and fragments are separated on a gel according to length, the particular fragment from the individual with the mutant allele will appear at a different position on the gel than the fragments from normal DNA. The resulting variation in length of a specific fragment is called a restriction fragment length polymorphism.

These polymorphic alleles are inherited in a Mendelian fashion. Since there are many RFLPs and many of them are common, RFLPs are very useful for mapping loci for genetic disorders.

Where an RFLP can be shown to be closely linked to the locus for a genetic disorder, the marker can then be used in a particular family to determine the probability that an individual actually has the gene for that disorder. Thus, where the likelihood for an autosomal dominant disorder is 50 per cent by Mendelian rules, the probability of a person actually having the gene can be revised downward or upward according to which linked polymorphism is present. Occasionally an RFLP will be within the gene and will predict the presence of the gene with virtual certainty.

20. Joseph Palca, "National Research Council Endorses Genome Project" (1988) 331:6156 *Nature* 467.

21. Joseph Palca, "Human Genome Organization Is Launched with a Flourish" (1988) 335:6188 *Nature* 286; G. Christopher Anderson, "Genome Project: Howard Hughes Gets HUGO off the Ground" (1990) 345:6271 *Nature* 100. It is interesting to note that as printed information, these three billion base pairs of the human genome sequence would fill "200 volumes the size of the Manhattan telephone book," "New Tools for Genome Study Being Made" (1988) 24:32 *Medical Post* 28.

22. As of 1988 the chromosomal location of over 1,215 human genes was known (of the approximately 100,000 estimated to exist). Congress of the United States, Office of Technology Assessment [hereinafter OTA], *Mapping Our Genes: Genome Projects — How Big, How Fast?* (Baltimore: Johns Hopkins University Press, 1988) at 4.

23. See Thomas D. Gelehrter and Francis S. Collins, *Principles of Medical Genetics* (Baltimore: Williams & Wilkins, 1990) for details.

V. The Changing Practice of Medical Genetics

Information from mapping can be used in a number of situations. For Mendelian disorders, it can be used prenatally to determine whether a foetus has the disorder.²⁴ After birth, it can confirm a diagnosis or detect the presence of a disease before signs are evident (pre-symptomatic testing). An example of the latter is its use in Huntington's disease²⁵ where, if the person inherits the gene and lives long enough, he or she will develop the disease. Testing may also be done to detect normal couples of which both individuals are carriers for recessive disorders. They may use this information to make reproductive decisions. Lastly, testing may be used to determine whether an individual has a genetic marker for a multifactorial disease that influences the probability of the individual's getting the disease.

In the past, there were few disorders having a known gene product that could confirm the presence of a mutant gene. Thus, disorders were first established as Mendelian on the basis of family studies. Then one could predict, from Mendelian principles, the chance that an affected person or two carrier parents would have an affected child. Now, the capacity to locate a gene or a marker close to the gene for the disease will greatly improve the precision of these predictions, depending on how close the linked marker is to the gene. What will be profoundly changed in medical genetics is that many more genetic loci will be discovered that can be used in prenatal and pre-symptomatic testing and in population screening. Some of these disorders will not be serious. Furthermore, some of the same sources of uncertainty remain, that is, those that are due to variable expressivity, to reduced penetrance and to the general complexity of common multifactorial disorders.

VI. Gene Therapy

Where the sequence of DNA bases is known, it is possible to change it in a directed way. This will eventually provide us with the means to treat or cure genetic disease. Genes can be isolated, together with their adjacent DNA containing the important regulatory information. It will then be possible to insert "normal" genes into cells taken from a patient who lacks the genes or who has them in an abnormal form. Gene therapy at present is done only in somatic cells. Unlike germ-cell modification, somatic-cell modification is not passed on to future generations.²⁶ Even

24. The purpose of prenatal diagnosis is to permit couples or individuals, who are at risk for the transmission of genetic diseases, to undertake having children. With respect to cystic fibrosis, see S. Blakeslee, "New Techniques Help Researchers Track Gene Defects," *International Herald Tribune* (14 September 1989) 7; P.N. Goodfellow, "Cystic Fibrosis: Steady Steps Lead to the Gene" (1989) 341:6238 *Nature* 102.

25. See J.-G. A., "Chorée de Huntington: test prédictif offert" (1989) 24:7 *Le médecin du Québec* 87.

26. OTA, *Human Gene Therapy: Background Paper* (Washington, D.C.: OTA, 1984) at 6.

though at present germ cell-line alteration is not possible in humans, there is a remote possibility of inadvertently affecting the germ line during somatic therapy which, we must remember, is still in the experimental stages of clinical application. It is being considered only for treatment of individuals with one of a few disorders that seem particularly amenable to this approach.²⁷ It may eventually be possible (although not practical) to apply gene therapy to the treatment of embryos at the pre-implantation stage (during the fourteen-day period following fertilization).²⁸

In April 1988, delegates of the seven industrialized nations attended the Fifth International Summit Conference on Bioethics on the mapping of the human genome. They agreed that "there are no intrinsic limitations to the acquisition of knowledge of the human genome and that research in this area should be strongly encouraged."²⁹ They also held that gene therapy of somatic cells should be judged on the same basis as other experimental medical treatments. However, they stated that there were neither medical nor ethical justifications for the intentional genetic manipulation of human germ-line cells at this time. The Medical Research Council of Canada, in its report, recognizes the specificity of these scientific endeavours as being distinct from research in human beings generally. The Council adopted the following position on research protocols in human somatic gene therapy: "gene transfer should only be considered for diseases which meet all the following criteria: they are caused by a defect in a single gene; they cause a liveborn human being to suffer severe debilitation or early death; [and] they cannot be treated successfully by any other means."³⁰ The Council committee studying this issue agreed that there is no indication, presently, for germ cell-line therapy or for any types of gene transfer to enhance functions, as opposed to curing severe debilitating diseases.³¹ This position is consistent with that of United States commissions studying human gene therapy³² and with that taken by the 1982 President's Commission for the Study of Ethical Problems in Medicine and Biomedical

27. Joseph Palca, "Gene Transfer to Humans Approved in the Face of Advice" (1988) 335:6191 *Nature* 577; Joanne Silberner, "Finally, Putting Genes into Humans" *US News and World Report* (17 October 1988) 66, where it was reported that terminal cancer patients may soon receive altered versions of their tumour-fighting cells. See also Jean L. Marx, "Gene Transfer Is Coming on Target" (1988) 242:4876 *Science* 191; Diane Gershon, "Genetic Engineering: Transfer Study Expands" (1990) 344:6266 *Nature* 483.

28. See generally "Preimplantation and Early Post-Implantation Diagnosis" (1987) 2:5 *Human Reprod.* 399; R.G. Edwards, "Diagnostic Methods for Human Gametes and Embryos" (1987) 2:5 *Human Reprod.* 415.

29. Alexander M. Capron, "The Rome Bioethics Summit" (1988) 18:4 *Hast. Cent. Rep.* 11 at 12. See also International Conference on Bioethics, *The Human Genome Sequencing: Ethical Issues* (Brescia, Italy: Clas International, 1989) at 291.

30. Medical Research Council of Canada, *Guidelines for Research on Somatic Cell Gene Therapy in Humans* (Ottawa: Supply and Services Canada, 1990) at 12.

31. *Ibid.*

32. *Supra*, notes 15 and 26.

and Behavioral Research, in the United States³³ More recently, the Science Council of Canada constituted a multidisciplinary group of experts to study advances in human genetics and their implications with the goal of developing a national health policy in genetic medicine.³⁴

The continental European countries are much more cautious in their attitudes to gene alteration. The European Medical Research Councils have approved somatic gene therapy.³⁵ Nevertheless, as will be seen in the following study of human dignity and of the notion of genetic "normality,"³⁶ European countries such as France,³⁷ Switzerland³⁸ and West Germany³⁹ favour a more restrictive application of the new human genetics.

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33. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research [hereinafter President's Commission], *Splicing Life* (Washington, D.C.: The Commission, 1982); see also President's Commission, *Screening and Counseling for Genetic Conditions* (Washington, D.C.: The Commission, 1983).
 34. Science Council of Canada, *Genetics in Canadian Health Care* (Ottawa: Supply and Services Canada, 1990).
 35. See "Gene Therapy in Man: Recommendations of the European Medical Research Councils" (1988) 11:8597 *Lancet* 1271 at 1272: "Only somatic cell gene therapy, resulting in non-heritable changes to particular body tissues, should be contemplated. Germline therapy, for introduction of heritable genetic modifications, is not acceptable."; *Contra*: Commission of the European Communities, *Modified Proposal for a Council Decision: Human Genome Analysis*, COM (89) 532 final, 13 November 1989 at s. 4.4.4: "That the development and the application of somatic gene therapy are not provided for within the framework of the present programme." Not only will no monies be provided for somatic therapy but "the contracting parties undertake to abstain from all research seeking to modify the genetic constitution of human beings by alteration of germ cells or of any stage of embryo development which may make these alterations hereditary" (s. 4.4.2).
 36. Below, Chapter Five.
 37. Conseil d'État, *Science de la vie: De l'éthique au droit*, 2d ed. (Paris: La Documentation française, 1988) at 84, takes the position that all germ-line alterations should be prohibited. It also recommends prohibiting genetic diagnosis of preimplantation embryos by embryo biopsy. This position is similar to that taken by the Comité National d'Éthique in its *Opinion relative to research work on human embryos in vitro and use thereof for medical and scientific purposes* of December 1986 (reproduced in Comité consultatif national d'éthique pour les sciences de la vie et de la santé, *Avis de recherches sur l'embryon* (Vendôme, France: Actes du Sud et Inserm, 1987) at 73). See also G. Huber, *Patrimoine génétique et droits de l'humanité* (Livre blanc des recommandations) (Paris: Osiris, 1990).
 38. Commission d'experts pour la génétique humaine et la médecine de la reproduction [hereinafter Commission d'experts], *Rapport au Département fédéral de l'intérieur et au Département de la justice et police* (Berne, 19 August 1988) at 97, takes the position that somatic cell therapy should be limited to cases of grave hereditary disorders. Germ-line therapy on gametes or embryos and non-therapeutic genetic manipulations will be prohibited. This opinion is particularly interesting as it is based on the Council of Europe's equation between the right to dignity and genetic heritage (see below, Chapter Three).
 39. *Fécondation in vitro, analyse du génome et thérapie génétique* (Benda report) (Paris: La Documentation française, 1987) considered that somatic cell therapy is still experimental and thus subject to the mandatory rules and protocols on human experimentation. Because germ-line research would involve the use of embryos and their possible destruction in experiments, it was not justified. The Commission recommended prohibiting germ-line experiments or treatments. This position was reaffirmed in the recent Report of the Enquete Commission to the Bundestag of the Federal Republic of Germany [hereinafter Enquete Commission], *Prospects and Risks of Gene Technology*, in "A Report from Germany" (1988) 2:3 *Bioethics* 254, which, at 257, considers that the natural development of human beings is a measure of their humanity. Like the proposed *Embryo Protection Law* of 1986, it would totally prohibit even therapeutic experimentation on human germ lines (at 261); see also Hans-Martin Sass, "A Critique of the Enquete Commission's Report on Gene Technology" (1988) 2:3 *Bioethics* 264 at 273.

VII. Conclusion

The foregoing overview demonstrates that the application of molecular biology to the investigation of genetic disorders not only provides us with new options but also creates uncertainty. The explosion of knowledge has widened the gap between our ability to identify and our ability to understand and treat genetic disorders.

The number of disorders for which prenatal and presymptomatic testing can be done is rapidly increasing. The ability to test for genetic loci that increase our susceptibility to developing common disorders, or to having children that develop them, could bring most of the human population under genetic scrutiny. Education of both health care professionals and the public is urgent if we are to avoid the detrimental fallout of this scrutiny.⁴⁰

40. Neil A. Holtzman, "Recombinant DNA Technology, Genetic Tests, and Public Policy" (1988) 42:4 *Am. J. Hum. Genet.* 624.

CHAPTER TWO

The Genome and the Gene Pool

I. Introduction

As mentioned earlier,⁴¹ the Parliamentary Assembly of the Council of Europe recommended in 1982 that the Committee of Ministers "provide for explicit recognition in the European Convention on Human Rights of the right to a genetic inheritance which has not been artificially interfered with, except in accordance with certain principles which are recognised as being fully compatible with respect for human rights."⁴² Neither the report of the hearing,⁴³ which preceded the drafting of the recommendation, nor the recommendation itself elaborated on the meaning of genetic heritage, that is, whether it referred to the genome (an individual's genetic material) or the gene pool (the sum of the genomes in the population). What then are the common, scientific and legal notions of genetic heritage?

41. *Recommendation 934, supra*, note 3.

42. *Ibid.* s. 7(b). An exception to non-interference was for prevention and therapy where there were clear and scientific reasons. See the discussion in Chapter Three. Similarly, His Holiness Pope John Paul II in his *Instruction* of 1987, while condemning most forms of research and the clinical applications of reproductive technologies and of genetic engineering, specifically approved the possibility of treating genetic disease *in utero* if it is in the interest of the child to be born. Congregation for the Doctrine of the Faith, *Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation* (Vatican City: Vatican Polyglot Press, 1987) at 14 (prenatal diagnosis):

Such diagnosis is permissible, with the consent of the parents after they have been adequately informed, if the methods employed safeguard the life and integrity of the embryo and the mother, without subjecting them to disproportionate risks.

At 15-16 (human embryo):

A strictly therapeutic intervention whose explicit objective is the healing of various maladies such as those stemming from chromosomal defects will, in principle, be considered desirable, provided it is directed to the true promotion of the personal well-being of the individual without doing harm to his integrity or worsening his conditions of life. Such an intervention would indeed fall within the logic of the Christian moral tradition.

43. Council of Europe, P.A., *Genetic Engineering: Risks and Chances for Human Rights*, European Parliamentary Hearing, Copenhagen, 25 and 26 May 1981 (Strasbourg: The Council, 1981).

II. Common Usage of Heritage

In popular usage, heritage is seen as an estate, a right of endowment inherited from one's ancestors. This individualistic notion of heritage as property is the most commonly known concept. Nevertheless, the etymological origins of the word encompass a figurative meaning that includes the notion of a common heritage of humankind, such as discoveries in science, or the culture or economy of a nation. Even in common usage, there is a biological interpretation of heritage, defined as the inherited characteristics as expressed in the outward appearance of an individual (the phenotype).⁴⁴

III. Scientific Usage

Because the population gene pool is made up of individual genomes, heritage is, for the biologist, both a collective and an individual notion. There is also a time element connecting the gene pool and the genome. Diversity in the gene pool arises over time through the process of mutation. Furthermore, in each generation the diversity between individuals is increased by the process of crossing over during meiosis. Recall that the egg or the sperm, produced by meiosis, contains a mixture of the chromosomal material of that person's parental chromosomes.⁴⁵ As a result of the biological processes of mutation and meiosis, each individual is unique and each offspring is different from his or her parents.

Yet, there is both a spatial and temporal connection between the genome and the gene pool. This universal, ancestral filiation makes the human gene pool both individual in expression and supranational in origin.⁴⁶ This is important in understanding the effects of germ-line and somatic-cell gene therapy.⁴⁷ Germ-line therapy would lead to

44. See generally *Webster's Third New International Dictionary of the English Language unabridged* (Springfield, Mass.: Meriam-Webster, 1986): "[1]b: anything derived from one's father or ancestors: Heritage c: an inheritance from the past" at 1656; *Larousse de la langue française: lexis* (Paris: Librairie Larousse, 1979, 1989): "2. Ce qui est transmis par les parents, par la génération antérieure" at 896; Paul Robert, *Petit Robert I: dictionnaire alphabétique et analogique de la langue française* (Paris: Le Robert, 1988): "Biol. Le patrimoine héréditaire de l'individu, l'ensemble des caractères hérités" at 1378.

45. See above, Chapter One.

46. André Langaney, "La diversité génétique humaine: considérable et mal connue" in *Génétique, procréation et droit* (Paris: Actes Sud, 1985) at 349; see also C.B. Stringer and P. Andrews, "Genetic and Fossil Evidence for the Origin of Modern Humans" (1988) 239:4845 *Science* 1263.

47. *Human Gene Therapy*, *supra*, note 26 at 31.

inherited changes and could therefore have an impact on the future population.⁴⁸ As mentioned earlier,⁴⁹ somatic-gene therapy affects only the individual concerned and would have no immediate, direct effect on the mix of genes in the human population. Yet, ultimately, the success of somatic therapy would lead to the survival of patients who would otherwise die. It would allow such individuals to transmit their genes to the next generation, thus increasing the frequency of the mutant gene.⁵⁰ Where descendants of such individuals develop the same disorder as their ancestors, they would also require treatment. In this way, while germ-line therapy would change the gene pool in a direct way, somatic-cell therapy would change it indirectly.

IV. Legal Notions of Heritage

The legal notions of heritage also reflect a diversity of interpretations. They traditionally restrict the scope of heritage in the private law domain to property of economic value, and in the public law domain to property of common interest. More recently, the notion of the public domain has been extended to a more universal form. In international law it includes property that is the common heritage of humankind.

A. Private Law

Beginning with the private law domain, the Roman law protected the family *patrimonium*. While the Quebec and French Civil Codes do not explicitly define *patrimoine*, it is seen as a universality of rights or property with an economic value whose assets and liabilities cannot be disassociated. It cannot be divided, nor can it be transmitted to another during a person's life. Every person can have only one *patrimoine* whose character is principally seen as pecuniary in nature. Moreover, rights of *patrimoine* often denote possession or ownership in the physical sense, as opposed to extra-patrimonial rights such as personal rights, innate rights and legal actions in relation to civil status.⁵¹

48. *Ibid.* This could lead to loss of genetic diversity, but such an effect would be insignificant. This is because most disease is multifactorial and gene therapy could only be applied to some single gene disorders, which are rare. The loss of genetic diversity in the gene pool would more likely be the result of "relaxing historic selection pressures on the human population through changes in the environment, sanitation, and health care" (at 31) than from deliberate intervention on an individual level.

49. See above, Chapter One.

50. Of course, the same is true of conventional therapy for diseases with a genetic basis.

51. See generally, Quebec Research Centre of Private and Comparative Law, *Private Law Dictionary and Bilingual Lexicons* (Montreal, Que.: The Centre, 1988); Henry Campbell Black, ed., *Black's Law Dictionary*, 5th ed. (St. Paul, Minn.: West Publishing, 1979) at 1015: "Patrimonium: that which is capable of being inherited. The private and exclusive ownership or dominion of an individual"

Yet, like the notion of real or personal property in the common law, the legal notion of heritage is no longer necessarily restricted to inherited property or to property in its economic sense. Nor is it so clearly distinct from personal rights as witnessed by the emergence, in both systems, of mixed rights such as those pertaining to intellectual property (for example, patents and copyright). Nevertheless, we shall see that the adoption of a private law approach mandating a property interest or a right in one's genome is problematic.

B. Public Law

The traditional legal notion of public property is: that which is in the public domain or is subject to public trust, *res nullius* (things without an owner) and *res communis* (things belonging to all). In particular, the air, the sea and outer space have historically been considered as *res communis* — incapable of individual ownership, and therefore inappropriable, indivisible, imprescriptible and inalienable.⁵² State regulation has severely curtailed the ambit of these traditional notions.⁵³ As with a private law approach, it will be argued that a strictly public law approach to genetic material or information is also problematic.

C. International Law

Another legal interpretation of property in public law is found in an international concept that emerged during the nineteenth century. It proposed the notion of common ownership or public interest in the "common heritage of mankind." Inspired by the work of Grotius, the first recognition of this common heritage of humankind was in relation to the sea. The sea was considered *res communis*, so that countries with shorelines had rights of servitude only over their own territorial waters. In modern international law, this respect for the common heritage of humankind requires a sharing between nations and a safeguarding of resources for future generations.⁵⁴

The common factors are that: utilization must be peaceful; access must be open to those who have that right who, in turn, must respect the rights of others; sharing must be equal; and, owing to its indivisible character, administration of that which is *res*

52. OTA, *New Developments in Biotechnology: Ownership of Human Tissues and Cells* (Washington, D.C.: U.S. Government Printing Office, 1987); Marie-Angèle Hermitte, "Histoires juridiques extravagantes: la reproduction végétale" at 40 and "Le concept de diversité biologique et la création d'un statut de la nature" at 238, as well as Catherine Labrusse-Riou, "Servitude, servitudes" at 308, all three texts found in Bernard Edelman and Marie-Angèle Hermitte, eds, *L'homme, la nature et le droit* (Paris: Christian Bourgois, 1988).

53. See generally Henri Lepage, *Pourquoi la propriété?* (Paris: Hachette, 1985); "Destins du droit de propriété" (1985) *Droits* (Revue française de théorie juridique) (Paris: P.U.F., 1985).

54. Alexandre-Charles Kiss, "La notion de patrimoine commun de l'humanité" (1982) II, 175 *RCADI* 99.

nullius must be in the interest of the common welfare.⁵⁵ This international concept stems from the need to prevent the private ownership of things of communal interest and to preserve for the future things that are of international interest. Like the concept of the trust in private law (once limited to "things" [*res*] and now extended to interests and rights), the concept is akin to that of the "public" trust. This trust serves to assist in the transmission of property or other interests from one generation to another.

The international conventions on the Law of the Sea,⁵⁶ or of the cultural or natural heritage of humankind,⁵⁷ have recognized the common contribution and interests of peoples or countries and the common need to share and preserve these heritages. While such "capital" can remain in public or private hands, the state has an obligation to define, identify, protect and conserve such property for future generations.⁵⁸ Thus, even such a vague notion as the "cultural property belonging to any people"⁵⁹ has been considered as included in the cultural heritage of humankind. In Europe, the Parliamentary Assembly of the Council of Europe has called on the "governments of member states to recognise that the European cultural heritage belongs to all Europeans."⁶⁰ According to UNESCO, "[a]s the testimony of the creative genius and the history of peoples, cultural property is a basic element of their identity and full enjoyment of this heritage is for each people an indispensable condition for its self-realisation."⁶¹ Yet, in practice, the concept is often limited to national legal protection of the cultural heritage.⁶² Even so, the obvious lack of clarity about what actually falls within the definition of such a heritage makes definitive legal obligations between nations extremely problematic. The concept on an international level remains largely a "political" one.⁶³

Although initially restricted to the protection of flora and fauna,⁶⁴ the international concept of the common heritage of humankind could be extended to include human "genetic heritage." Traditionally, plants and animals were considered as *res nullius*, appropriable by all and susceptible to destruction. This mandated their protection and

55. *Ibid.*; see also K. De Jager, "Claims to Cultural Property under International Law" (1988) 1 Leiden J. Int'l L. 183.

56. *United Nations Convention on the Law of the Sea*, U.N. Doc. A/Conf.62/122 (1982).

57. De Jager, *supra*, note 55.

58. Kiss, *supra*, note 54 at 129ff.

59. *Convention for the Protection of Cultural Property in the Event of Armed Conflict* (The Hague, 1954) (1956) 249 U.N.T.S. 240.

60. Council of Europe, P.A., 35th Sess., Pt II, *Text Adopted, Resolution 808 (1983) on the Return of Works of Art*, s. 10.

61. UNESCO Committee of Experts to Study the Question of the Restitution of Works of Art, Venice, 1976, SHC-76/CONF.615/5, s. 19.

62. See, e.g., *Cultural Property Act*, R.S.Q., c. B-4.

63. See De Jager, *supra*, note 55, quoting Larschian and Brennan at 191.

64. The protection of the flora and fauna was based on the fear that the creation of new micro-organisms, of hybrids or of synthetically based organisms could lead to the disappearance of "original" stock whose genetic value had not as yet been realized.

management in the common interest.⁶⁵ Humanity, in the global sense then, is the trustee of those resources, although international organizations may set the principles to be implemented by adhering states. Such protection against degradation, exploitation and waste of the natural heritage is both "transspatial" and "transtemporal" since it is not limited by geographic or political borders and it concerns future generations.⁶⁶

The 1982 Council of Europe recommendation on genetic engineering of micro-organisms of plant and animal species extended this concept to human beings. Could the protection of the *human* genetic heritage be possible through the application of this international legal notion of common heritage or through that of private or public law?

D. An Integrated Approach

It may be difficult to apply this particular international law notion of the common heritage of humankind to human genetics, since the human genome (individual) or the gene pool (communal), would first have to be considered as *res communis* (owned by all) or as *res nullius* (not owned by anyone). Secondly, there are certain conceptual and political problems associated with the notion of common participation in the stewardship of the heritage, all the more evident in the absence of shared ownership. Integration is the natural genetic way; apartheid is cultural ignorance. Finally, the determination of what would be considered as peaceful use and what would constitute abuse requires the delineation of societal goals with respect to human genetics.⁶⁷ Therefore, the question involves a determination of "the extent to which our collective gene pool is public property, which we hold in trust for the future, and the extent to which the very personalized packages into which it is subdivided precludes treating it as a public resource."⁶⁸

In 1987, the American Office of Technology Assessment alluded to the possibility of congressional action recognizing "that any cell line be presumed to be in the public domain,"⁶⁹ thus barring anyone from claiming property rights to those products. Similarly, the Committee on Mapping and Sequencing the Human Genome of the United States National Research Council recommended in 1988 "that human genome

65. See generally Marie-Angèle Hermitte, *Le droit du génie génétique végétal* (Paris: Librairies Techniques, 1987) and, e.g., the *Environmental Quality Act*, R.S.Q., c. Q-2.

66. *Convention for the Protection of Cultural Property in the Event of Armed Conflict*, *supra*, note 59 at 240.

67. Below, Chapters Five and Six. See also (Sept. 1988) Forum (Council of Europe) for a special issue on genetics (Animal, vegetable, environmental and medical).

68. James V. Neel, "Social and Scientific Priorities in the Use of Genetic Knowledge" in Bruce Hilton et al., *Ethical Issues in Human Genetics: Genetic Counseling and the Use of Genetic Knowledge* (New York: Plenum Press, 1973) 353 at 358.

69. *New Developments in Biotechnology*, *supra*, note 52 at 17.

sequences should be a public trust and therefore should not be subject to copyright.”⁷⁰ This possibility was also raised by the Committee on Mapping and Sequencing of the American Society of Human Genetics when it solicited comments from its members on the public trust position, namely, “an expression of belief that the human genome sequences should be a public trust and therefore not be subject to copyright.”⁷¹ On the other hand, the Ad Hoc Committee on DNA Technology of the Society held that “[b]anked DNA is the property of the depositor unless otherwise stipulated.”⁷² The two approaches from the same Society need not be seen as contradictory. In fact, it could be argued that one’s individual control over the uses of his or her tissues and cells is not incompatible with the notion of the human genome itself being considered a public trust. It should be possible to balance the notions of individual “genetic control” together with public stewardship of the larger “gene pool” or human genome without recourse to property law. Such an approach would parallel the actual biological reunion of the individual pattern and gene pool source found in the human person.

V. Conclusion

The difficulties and shortcomings of applying the private, public or even international law concept of the common heritage of humankind to human genetics stem from the fact that such notions are rooted in their own historical and cultural contexts. The implications of human genetics affect the personal, the public and, with the mapping of the genome, the international domain. Thus, a more innovative approach to the concept of heritage is necessary — one that respects the person in the totality of his or her being and as a member of society.

The choice must be integrated at both the provincial and the national level. Moreover, individual control and public trust concepts must conform to internationally shared principles. In this way, the notion of the human genetic heritage may acquire the necessary specificity for adequate and real protection.

As mentioned earlier in this chapter, the Parliamentary Assembly of the Council of Europe recommended that genetic heritage be protected. We have explored the concept of genetic heritage and have seen that it is both an individual and a collective notion, consisting of the genome and the gene pool.

Our next task is to examine the question of why the genetic heritage needs protection. The Parliamentary Assembly of the Council of Europe considered it

70. *Supra*, note 15 at 100.

71. Elizabeth M. Short, “Proposed ASHG Position on Mapping/Sequencing the Human Genome” (1988) 43:1 *Am. J. Hum. Genet.* 101 at 102.

72. Ad Hoc Committee on DNA Technology, American Society of Human Genetics, “DNA Banking and DNA Analysis: Points to Consider” (1988) 42:5 *Am. J. Hum. Genet.* 781 at 782.

necessary to protect human dignity. In the next two chapters we will explore the meaning of human dignity in the context of human genetics, first from the perspective of international law, and then from a constitutional point of view.

CHAPTER THREE

Human Dignity and Genetics – The International Context

I. Introduction

“Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world” With these majestic and inspiring ideals, the *Universal Declaration of Human Rights* was proclaimed by the United Nations General Assembly on December 10, 1948. Article 1 of that same text affirms that “[a]ll human beings are born free and equal in dignity and rights” and article 27 that “[e]veryone has the right freely to . . . share in scientific advancement and its benefits.”⁷³ Similarly, the Preamble to the European Convention on Human Rights of 1950 and the *International Covenant on Economic, Social and Cultural Rights*⁷⁴ of 1966 recognize this foundation. The latter states that all legal rights derive from the inherent dignity of human beings.⁷⁵ While Canada is a party to those two international covenants, the *Canadian Charter of Rights and Freedoms* does not adopt their terminology, nor does it explicitly refer to the notion of human dignity. In contrast, section 4 of the Quebec *Charter of Human Rights and Freedoms* guarantees that “[e]very person has a right to the safeguard of his dignity,”⁷⁶ without further qualification.

Those provisions concerning human dignity have not been authoritatively interpreted or applied by any of the competent, independent, international institutions.⁷⁷ In fact, as is evident from the very wording of the foregoing international texts, a respect for human dignity is seen as a *sine qua non* for the elaboration and construction of all other fundamental human rights. Human dignity being so basic in nature and the

73. *Supra*, note 1.

74. (1976) 993 U.N.T.S. 4.

75. See also the similar preamble to the 1966 *International Covenant on Civil and Political Rights* (1976) 999 U.N.T.S. 172 (“Recognizing that these rights derive from the inherent dignity of the human person”); *American Convention on Human Rights* (1969), art. 11(1): “Everyone has the right to have his honour respected and his dignity recognised”; *African Charter on Human and Peoples’ Rights* (1981), art. 5: “Every individual shall have the right to the respect of the dignity inherent in a human being.” Both the American Convention and the African Charter are reproduced in Council of Europe, *Human Rights in International law: Basic Texts* (Strasbourg: The Council, 1985) at 176 and 207.

76. R.S.Q., c. C-12. For a study of Canadian constitutional law, see below, Chapter Four.

77. Paul Sieghart, *The International Law of Human Rights* (Oxford: Clarendon Press, 1983) at 309. As regards the Quebec Charter, see Jean-Maurice Brisson, *Texte annoté de la Charte des droits et libertés de la personne du Québec* (Montreal: SOQUII, 1986).

source of all human rights, perhaps it is not deemed necessary to guarantee or limit that notion.⁷⁸ All human rights derive from respect for this inherent dignity.

That interpretation is supported in the literature which, in defining the basic policies for an international law on human dignity, maintains that the relevant perspective "rests on a conception of the universe in which the moral personality of man and his dignity and rights stand in the center."⁷⁹

Moreover, the strength of human rights, framed as they are in general terms, comes from their ethical and moral dimensions as distinct from other legal rules of a technical nature. Human rights function to mediate between the juridical, ethical and political domains, the result being a form of natural law. This natural law provides the principal framework for such mediation. The realization of the concept of human dignity is therefore variable in its content, depending on national and cultural needs and on differences in interpretation.⁸⁰

Finally, human rights exist in national and international constitutions not only to provide "some private immunity in relation to the authorities or to oblige the authorities to offer us protection against action of other citizens"⁸¹ or organizations of citizens, but also "to bring about certain positive conditions for the actual enjoyment of human rights."⁸²

In the medical context, the third General Assembly of the World Medical Association adopted an *International Code of Medical Ethics* in 1949.⁸³ The Assembly held that one of the imperative duties of the physician is to provide competent medical services "with compassion and respect for human dignity."⁸⁴ The 1981 *Declaration of*

78. Note, however, that respect for inherent dignity of the human person was specifically linked to protection of persons deprived of their liberty under art. 10(1) of the *International Covenant on Civil and Political Rights*, *supra*, note 75.

79. Myres S. McDougal, Harold D. Lasswell and Lung-Chu Chen, *Human Rights and World Public Order: The Basic Policies of an International Law of Human Dignity* (New Haven, Conn.: Yale University Press, 1980) citing M. Muskowitz at 373.

80. Mireille Delmas-Marty, "Un nouvel usage des droits de l'homme" in *Éthique médicale et droits de l'homme* (Paris: Actes Sud/INSERM, 1988) 313.

81. B. Elmquist, "Genetic Engineering: Risks and Chances for Human Rights — Legal Aspects: Possibilities of New Legislative Steps at National and International Level" in Council of Europe, *supra*, note 43, 203 at 207.

82. P. Leuprecht, intervention at Parliamentary Hearing in Council of Europe, *supra*, note 43 at 115. Such positive conditions are evident in the creation by a given state, for example, of the office of the ombudsman or of affirmative action programs.

83. Reprinted in "Medical Ethics Declarations" (1984) 31:3 *World Medical Journal* [back cover]. This Code was based on the 1948 *Declaration of Geneva* and revised at the 35th Assembly of the World Medical Association, in Venice in 1983.

84. *Ibid.* See a similar provision of the American Medical Association, *Principles of Medical Ethics* (Chicago: The Association, 1980).

Lisbon on the rights of the patient speaks of the right to die in dignity.⁸⁵ The revised *Declaration of Helsinki*⁸⁶ on biomedical research involving human subjects makes no explicit reference to a right to dignity. However, like the more specific Council for International Organizations of Medical Sciences (CIOMS) guidelines that followed in 1982,⁸⁷ the very foundation for elaborating the protection of human subjects is built on the inherent dignity of the human person.

Under the principles of international human rights law, human dignity and genetic heritage concern the status, protection and uses of, and access to, human genetic material. Thus, issues concerning the right to self-determination, to marry and to found a family, to life, to health, to be free from inhuman and degrading treatment and to respect for privacy and for family life could arise. These human rights have been extensively interpreted with respect to abortion.⁸⁸ But, as is evident with regard to reproductive technologies and the protection of human genetic material such as gametes or embryos, recourse to the protection offered by these rights in public international law would be indirect, incomplete and, in all likelihood, inadequate.⁸⁹ Indeed, as we shall now see, some of the arguments raised by the Parliamentary Assembly of the Council of Europe point to the need for precision in the delineation of human rights specific to reproductive technologies and to human genetics.⁹⁰

II. Rights in Genetic Heritage

The 1982 recommendation of the Parliamentary Assembly of the Council of Europe was the first to situate the notion of the inherent dignity of the human person specifically in the context of human genetic engineering.⁹¹ It considered that "the

85. Reprinted in "WMA's Declarations and Statements" (1982) 29:6 World Medical Journal 91. The Declaration was adopted at the 34th World Medical Assembly, Lisbon, Portugal, 1981. See also Canadian Medical Association, *Code of Ethics* (Ottawa: The Association, 1990), s. 18.

86. Recommendations Guiding Physicians in Biomedical Research Involving Human Subjects, adopted 1964 (am. Tokyo, 1975; am. Venice, 1983; am. Hong Kong, 1989). The text is reproduced in "World Medical Association Adopts Amended Version of the Declaration of Helsinki" (1990) 41:3 Int'l Dig. Health Leg. 530.

87. World Health Organization and Council for International Organizations of Medical Sciences, *Proposed International Guidelines for Biomedical Research Involving Human Subjects* (Geneva: CIOMS, 1982); see also Medical Research Council of Canada, *Towards an International Ethic for Research with Human Beings* (Ottawa: Supply and Services Canada, 1988) at 66, on the need for greater surveillance over the protection of dignity and privacy in epidemiological studies.

88. See *infra*, note 129, Chapter Four.

89. See Bartha M. Knoppers, "Reproductive Technology and International Mechanisms of Protection of the Human Person" (1987) 32 McGill L.J. 336 at 350-56 and its continuation by the same author in "L'adoption d'un code de conduite international en matière de technologies de la reproduction," in International Law Association, *Report of the Sixty-third Conference* (Warsaw, Poland: The Association 1988) at 879.

90. See *infra*, notes 103-108.

91. *Recommendation 934, supra*, note 3, s. 4(i). See also Knoppers, "Reproductive Technology," *supra*,

rights to life and to human dignity protected by Articles 2 and 3 of the European Convention on Human Rights imply the right to inherit a genetic pattern which has not been artificially changed.”⁹² To avoid any ambiguity, the Parliamentary Assembly recommended that “this right should be made explicit in the context of the European Convention on Human Rights.”⁹³

At the Parliamentary Hearings preceding the recommendation, there was a general acceptance of the notion that all rights derive from this inherent dignity and contribute to its meaning. The report of those hearings states as follows.

Among the fundamental human rights embodied in this convention, absolute priority is given to the right to life (Article 2) and to integrity of persons (Article 3); these rights, together with all the regulations contained in the convention and in its protocol signed in Paris on 20 March 1952, provide a highly refined concept of human dignity which has inspired the member states which have committed themselves under this, an international instrument, to respecting them and participating actively in their development.⁹⁴

The extensive advances in, and potential applications of, human genetics and DNA technology apparently inspired the Parliamentary Assembly to propose a more specific delineation of inherent dignity as a human right in Recommendation 934.⁹⁵

In 1986, in line with most national reports on the need to respect human embryos,⁹⁶ the Assembly passed Recommendation 1046 on the use of human embryos and fetuses for diagnostic, therapeutic, scientific, industrial and commercial purposes. It recommended that human embryos and fetuses be treated with the respect that is due to human dignity,⁹⁷ irrespective of their legal status. Furthermore, the first article of Recommendation 1046 reiterated the need to recognize “the right to a genetic inheritance which should not be artificially interfered with except for therapeutic purposes.”⁹⁸ Finally, in 1989, in Recommendation 1100 on the use of human embryos

note 89, where, while not referring to a right to inherit a genetic pattern, we argued that the rights to life, to integrity and to the inviolability of the human person have been recognized in international texts. See also Bartha M. Knoppers and Claude M. Laberge, “DNA Sampling and Informed Consent” (1989) 140:9 C.M.A.J. 1023, where we presented our position that the advent of somatic cell or of germ-line therapy does not change the necessity of protecting inviolability or of respecting integrity by obtaining informed consent from an individual prior to therapy or prior to any uses of a person’s genetic material. In fact, the use of molecular biology techniques in human genetics expands the scope of the need for informed consent.

92. Recommendation 934, *supra*, note 3, s. 4(i).

93. *Ibid.*, s. 4(ii).

94. D. Cucchiara, intervention at the Parliamentary Hearing, in Council of Europe, *supra*, note 43 at 81.

95. *Supra*, note 3.

96. See Knoppers, *supra*, note 89.

97. Council of Europe, P.A., 38th Sess., Pt II, Text Adopted, Recommendation 1046 (1986) on the Use of Human Embryos and Fetuses for Diagnostic, Therapeutic, Scientific, Industrial and Commercial Purposes, s. 10.

98. *Ibid.*, s. 1.

and foetuses for research purposes, the Parliamentary Assembly repeated its support of the former proposals in those earlier recommendations.⁹⁹

The Council of Europe, in Recommendation 1046, specified that there is a need for a legislative prohibition of abuses of human genetic engineering. Such abuses include the cloning of individuals, sex selection, the creation of chimeras, interspecies fertilization and other non-therapeutic genetic manipulations.¹⁰⁰ That recommendation has been unanimously supported by other European governmental commissions studying reproductive technologies and human genetic engineering.¹⁰¹

III. Consequences of Rights in Genetic Heritage

The Parliamentary Assembly, in its 1989 recommendations, supported its earlier proposals that there should be a right to an unaltered genetic heritage.¹⁰² It was specified at the hearings preceding the 1981 recommendation that this right would belong to "future generations,"¹⁰³ presumably including children already conceived but not yet born, to those embryos or gametes *in vitro* or in storage or to those children not yet conceived.

Who would be entitled to bring such a non-existing person's right to an unaltered genetic heritage before the courts? According to the rapporteur of the report, "perhaps [this would fall to] the authorities and in any case the persons themselves when once they have been born and if they felt themselves that they had been genetically engineered in an illegal manner."¹⁰⁴

In their 1982 recommendation on genetic engineering, the Council of Europe specifically recognized an exception to the generally recommended prohibition on

99. Council of Europe, P.A., 40th Sess., Pt III, *Text Adopted, Recommendation 1100 (1989) on the Use of Human Embryos and Foetuses in Scientific Research*, s. 2: "Noting the contents of the Council of Europe's Parliamentary Assembly Recommendation 934 (1982) and its proposals for the application of genetic engineering on the basis of respect for the genetic heritage of mankind, which shall not be interfered with in individuals save for clearly and scientifically demonstrated preventive and therapeutic purposes;"

100. *Ibid.*, s. 14(iv).

101. Benda report, *supra*, note 39 at 48: "L'utilisation des méthodes qui viennent d'être décrites constitue une atteinte particulièrement grave à la dignité de l'être humain. Résolution: Quelle que soit la méthode employée, le clonage d'êtres humains est inadmissible. L'est également la création de chimères et d'hybrides d'homme et d'animal." See also *supra*, note 35 and below, Chapter Five.

102. See *Recommendation 1100, supra*, note 99.

103. Elmquist, *supra*, note 81 at 208. That is to say, gametes in storage *ex utero* or in the gonads.

104. *Ibid.* at 209.

human genetic engineering. This was for prevention and therapy where a need was "clearly and scientifically demonstrated."¹⁰⁵

Such an exception called for criteria to decide what kinds of disorders would fall within its ambit. The 1986 Recommendation 1046 proposed drawing up a list for "those illnesses where therapy can be based on reliable means of diagnosis and reasonable guarantees of success. This list would be periodically updated to take account of new discoveries and scientific progress."¹⁰⁶

The rapporteur of the 1981 report preceding the adoption of Recommendation 934 specified that there would need to be general agreement for an illness to be included on the list.¹⁰⁷ The rapporteur also suggested that for diseases on the list, "authorised enforced genetic engineering should perhaps be considered. . . . A compromise might be a demand that the person in question accepted genetic engineering as a pre-condition for being allowed to have children."¹⁰⁸

Thus, there are two aspects to the proposals. The first is to prevent genetic manipulation that ought not to be done, and the second is to ensure that genetic manipulation is done only where not doing so would result in the passing on of genes that could produce a serious illness.

Undoubtedly, there is a need to establish legal limits to deter possible abuses of genetic engineering. Such is the case presently with the recommendation of the Parliamentary Assembly to prohibit certain forms of non-therapeutic genetic experimentation.¹⁰⁹ Nevertheless, the promotion of such protection as a legal "right" not to inherit certain genes could lead to horrific consequences. If one were to adopt the interpretation suggested in the 1981 report, the ensuing consequences could include scientific or personal lobbying with respect to the inclusion or exclusion of certain diseases on the list, pre-conception screening for genetic suitability, enforced treatment for listed diseases and suits against actual or potential parents. What types of illnesses could be considered sufficiently serious so as to require genetic engineering? Should the willingness to use genetic engineering be a pre-condition for the "privilege" of conception? Could one claim against one's parents or against the state for failing to act in the interests of the child by not having chosen to make use of genetic engineering?¹¹⁰ The right to inherit an intact genome, the inherent dignity of the human person and the framing of some form of legal protection are issues that cannot be disassociated.

105. *Recommendation 1100, supra*, note 99, s. 2. This recommendation was approved in the 1986 recommendation on the use of human embryos and fetuses.

106. *Supra*, note 97, Appendix, B(iv).

107. Elmquist, *supra*, note 81, by reference from s. 10 of *Recommendation 1046* to the Appendix, B(iv).

108. Elmquist, *supra*, note 81 at 208.

109. *Recommendation 1046, supra*, note 97.

110. This would seem to be the logical conclusion from the 1981 report, Council of Europe, *supra*, note 43. It is also a position held by certain American authors such as Margery W. Shaw, "Conditional Prospective Rights of the Fetus" (1984) 5 J. Legal Med. 63.

IV. Critique of Genetic Rights

Currently, pre-conception choices are left to couples within the limits of state regulation and available medical services and information.¹¹¹ During pregnancy, recourse to abortion and medical treatment and the choice of personal life-style have, on the whole, been seen as falling within the right of the woman to liberty and personal privacy.¹¹² State interest in protecting potential "persons" is balanced against those rights. A result of this interest is an increasing gradation of state surveillance over the woman and protection of the foetus as the foetus becomes viable.¹¹³ Finally, where fertilization occurs *in vitro*, direct state intervention to protect the embryo by legislation is still the object of discussion.¹¹⁴

While certain forms of non-therapeutic genetic experimentation have been universally condemned,¹¹⁵ prior to Recommendations 934 and 1046 of the Parliamentary Assembly, a right to dignity in relation to the inheritance of a particular genome had not been mentioned. The possible interpretations to which the adoption of such a right may lead having been seen, its rationale should be questioned. A more profound discussion and analysis are required before that right becomes enshrined.

Any future recommendation should consider the following points as well. First, there are relatively few disorders to which somatic gene therapy, or one day perhaps

111. Bartha M. Knoppers, "Modern Birth Technology and Human Rights" (1985) 33 Am. J. Comp. L. 1, Knoppers, *supra*, note 89 and Bartha M. Knoppers, *Conception artificielle et responsabilité médicale: une étude de droit comparé* (Cowansville, Que.: Yvon Blais, 1986).

112. Sanda Rodgers, "Fetal Rights and Maternal Rights: Is There a Conflict?" (1986) 1 C.J.W.L. 456; see also Chapter Five, below.

113. Rodgers, *supra*, note 112; see also Jean-Louis Baudouin and Catherine Labrusse-Riou, *Produire l'homme: de quel droit?* (Paris: P.U.F., 1987) and Law Reform Commission of Canada, *Crimes against the Foetus*, Working Paper 58 (Ottawa: The Commission, 1989). The foetus is also protected indirectly in private law. Thus, where health care workers negligently fail to inform parents of reproductive risk, or misinform them, they or their disabled child born as a result may bring a suit in "wrongful birth" or "wrongful life." See below, Chapter Five, and Knoppers, *supra*, note 111.

114. Knoppers, *supra*, note 89.

115. *Supra*, notes 94, 97; see also J. Dausset, "Éditorial: Les droits de l'Homme face à la science" (1989) 3:3 Cahiers du M.U.R.S. at article X. [U.M.S.R. (Universal Movement for Scientific Responsibility) proposes to add a new article to the *Universal Declaration of Human Rights*] "Scientific knowledge should be used only to promote dignity and preserve the integrity and the future of man. No-one can hinder the acquisition of scientific knowledge." U.M.S.R. also proposes the adoption by the United Nations Organization of the following principles:

- Sources of energy should be used only for the benefit of mankind, without damaging the biosphere.
- Human genetic inheritance, given our present level of knowledge, should not be modified.*
- The human body — cells, tissues or organs — has no price, and thus cannot be a source of profit.

* This does not exclude the treatment of genetic diseases by introducing genes into those cells of the patient which are involved in sexual reproduction.

germ-line therapy, will be applicable, because gene therapy is only applicable to single gene disorders where the gene locus has been identified. Most diseases are not due to a single gene. Second, when direct intervention does become possible, it may instead take the form of pre-fertilization, pre-implantation or *in utero* genetic selection, rather than gene therapy. Thus, the areas in which respect for the inherent dignity of the human person will be important are the diffusion, communication and handling of genetic information, the freedom of procreative choices, the safeguards to be placed on DNA banking and, only rarely, genetic manipulation *per se*. These important areas involve choice and the provision of information to make such choice. In order to ensure the individuality of the person as well as the continuity of the human species, freedom of genetic choice needs to be legally protected, because individual choice is the basis of human dignity.¹¹⁶

Finally, respecting the dignity of the person in its substrate — the human gene — means respect for the person.¹¹⁷ The human person can be seen as having the following dimensions: organic, psychic and symbolic.¹¹⁸ These dimensions of body, mind and soul imply the need for reciprocity and sharing — a need that is specific to human beings. The obligation of reciprocity is a construct of the solidarity of human kinship in the Family of Man. These three dimensions of human dignity are inherent in the person and should be valued as priceless and ageless.

V. Conclusion

In the international context, we have seen the dangers of the interpretation of human dignity that concerns the “rights” to an unaltered genetic heritage.¹¹⁹ Under the guise of protection, such an interpretation would lead to the screening and selection of those individuals suitable to reproduce and, ultimately, to lawsuits within families and between generations. A new approach to defining dignity as the basic principle for human rights in the context of human genetics is called for. Dignity cannot exist independent of the individual. If we assume that the human gene, including the information it contains, is more than a substrate for the existence of the human person, then the individual’s freedom to control its expression during his or her life span will become the core of human dignity.

116. Oscar Schachter, “Human Dignity As a Normative Concept” (1983) 77 Am. J. Int’l L. 848.

117. Congregation for the Doctrine of the Faith, *supra*, note 42 at 8-9.

118. Jean-François Malherbe, *Pour une éthique de la médecine* (Paris: Larousse, 1987); Mary Warnock, “Do Human Cells Have Rights?” (1987) 1:1 Bioethics 1; Lucien Sève, *Recherche biomédicale et respect de la personne humaine: Explication d’une démarche* (Paris: La Documentation française, 1987); see also below, Chapter Six.

119. For an interpretation of international law and human rights in the context of human procreation and reproductive technology generally, see Knoppers, *supra*, note 89.

In Canada, the concept of human dignity has not been specifically studied by the courts in relation to human genetics. It has, however, been interpreted in the larger context of human rights under Canadian constitutional law. An examination of this interpretation in relation to those human rights may shed some light on alternative approaches.

CHAPTER FOUR

Human Dignity and Genetics

— The *Canadian Charter of Rights and Freedoms*

I. Introduction

As we have seen, public policy recommendations in genetics can have profound implications for the individual in his or her most intimate self. There is no doubt of the need to legislate in the future to protect the inherent dignity and self-worth of individuals with respect to their genetic heritage. But any such legislation must conform to the *Canadian Charter of Rights and Freedoms*. What guidance can be gleaned from the structure of the *Charter* and from Supreme Court of Canada decisions relevant to our subject? Let us examine the possible impact of the *Charter* on future legislative policies on human genetics by first discussing its scope.

Legal recourse under the *Charter* is possible when legislation or other governmental action has violated a protected right. Under section 32, the *Charter* prohibits unconstitutional actions by federal, provincial and territorial governments or government entities. In other words, it protects Canadians from government interference with the rights and liberties enunciated therein.¹²⁰ The *Charter* does not apply to non-governmental organizations. Where an infringement of human rights is alleged by an individual against another individual, or against a corporation or employer, provincial human rights codes would generally apply.

The Canadian *Charter* does not explicitly refer to the notion of human dignity. However, it is the fundamental theme that underlies the *Charter*. An important component of the inherent dignity of the person is freedom of choice in decision making. The corollary is that the state must respect individual choice.¹²¹

The theme of human dignity can be found in the sections of the *Charter* guaranteeing various rights and liberties. We will look at several of these: freedom of conscience and religion, and of association (section 2), the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice (section 7), the right to be secure against

120. *RWDSU v. Dolphin Delivery Ltd.*, [1986] 2 S.C.R. 573.

121. Luc Huppé, "La dignité humaine comme fondement des droits et libertés garantis par la Charte" (1988) 48 R. du B. 724.

unreasonable search and seizure (section 8), and the right to be equal before and under the law and to equal protection and benefit of the law without discrimination (section 15). These rights can be invoked by an individual in the area of human genetics, with regard to provincial or federal legislation or policies of government entities.

Taking each of these rights and freedoms in turn, we will briefly examine the scope of their interpretation, as found in certain decisions of the Supreme Court of Canada. Each interpretation will be followed by examples of how it might apply in the area of human genetics. Finally, even where legislation violates a *Charter* right, it could survive judicial scrutiny if it is considered a reasonable limitation of a right that can be demonstrably justified in a free and democratic society under section 1 of the *Charter*.

II. Freedom of Association and of Conscience and Religion

Protection under section 2 of the *Charter* includes freedom of association, conscience and religion. Freedom of association has been held to include those "collective activities which may be said to be fundamental to our culture and traditions and which by common assent are deserving of protection."¹²² The Court also suggested that a fundamental institution such as marriage "might well be protected by freedom of association in combination with other rights and freedoms."¹²³ Thus, any legislation linking the obtaining of a marriage licence to genetic status in order to prevent the transmission of genetic disease could run afoul of this protected sphere of activity.

Freedom of conscience and religion has received a wide interpretation by the Court. Its scope has been described as follows:

Freedom can primarily be characterized by the absence of coercion or constraint. If a person is compelled by the state or the will of another to a course of action or inaction which he would not otherwise have chosen, he is not acting of his own volition and he cannot be said to be truly free. One of the major purposes of the *Charter* is to protect, within reason, from compulsion or restraint. Coercion includes not only such blatant forms of compulsion as direct commands to act or refrain from acting on pain of sanction, coercion includes indirect forms of control which determine or limit alternative courses of conduct available to others.¹²⁴

This freedom has been held to extend to the expression of individual life-style¹²⁵ and to parental choices for their children in, for example, the area of education.¹²⁶

122. *Reference re Public Service Employee Relations Act (Alta.)*, [1987] 1 S.C.R. 313 at 401.

123. *Ibid.* at 406.

124. The words of Dickson C.J. in *R. v. Big M. Drug Mart Ltd.*, [1985] 1 S.C.R. 295 at 336-37.

125. *Attorney-General of British Columbia and Astaroff* (1983), 6 C.C.C. (3d) 498 (B.C.C.A.).

126. *R. v. Jones*, [1986] 2 S.C.R. 284.

Would this broad scope of parental freedoms be upheld in the face of legislation prescribing genetic testing prior to procreation? If it could be determined with certainty that a child would be born with severe malformations, would individuals of a certain religious faith still be free deliberately to conceive a child under the tenets of their faith? If such a choice were not based on religious precepts, could that same couple allege that any restriction of their freedom to procreate within marriage would violate the right to freedom of association?

III. Life, Liberty and Security of the Person

Triggering the operation of section 7 of the *Charter* involves a two-step process. First, it must be found that there has been a deprivation of the right to "life, liberty and security of the person"; second, this deprivation must be contrary to the principles of fundamental justice. The Supreme Court of Canada has enunciated that the three distinct elements of section 7 — life, liberty and security of the person — are independent interests that must be given independent significance.¹²⁷ However, Parliament could choose to infringe any of these rights if it did so in a manner consistent with the principles of fundamental justice.

It is difficult to imagine how the right to life could be invoked in the context of human genetics. The right of "everyone" to life has been held not to include the foetus.¹²⁸ Thus, it is difficult to see how the genome, gametes or embryos could be considered as being protected under the right-to-life provision in section 7.

A more likely avenue of contestation in the case of government intervention in the area of human genetics would be the *Charter* provisions concerning the right to liberty or to the security of the person. Madam Justice Wilson of the Supreme Court of Canada has described the scope of this right to liberty as including "... the right to make fundamental personal decisions without interference from the state."¹²⁹ Decisions about one's genetic health or that of one's offspring would certainly fall within the ambit of personal decisions. Mandatory screening of adults or adolescents to determine whether they are carriers of genetic disease would clearly be an interference with this right. The dignity and self-respect of those persons would be affected. Such legislation would infringe section 7 because that legislation "require[s] a person . . . to go through an identification process on pain of . . . [a sanction] for failure to comply."¹³⁰

127. *Singh v. Minister of Employment and Immigration*, [1985] 1 S.C.R. 177.

128. *Borowski v. Attorney General of Canada*, [1987] 4 W.W.R. 385 (Sask. C.A.), which contains an excellent review of the similar position taken world-wide by the courts. On November 16, 1989, the Supreme Court of Canada held, in *Tremblay v. Daigle*, [1989] 2 S.C.R. 530, that the foetus is not a legal person under Quebec civil law.

129. *R. v. Morgentaler*, [1988] 1 S.C.R. 30 at 166.

130. *R. v. Beare*; *R. v. Higgins*, [1988] 2 S.C.R. 387 at 388-89, where the Court did not dispute the holding of the Saskatchewan Court of Appeal but, in the particular "criminal" context of the case, held that the fingerprinting of suspects was a justifiable interference under s. 1 of the *Charter*.

But would the mandatory screening of, say, newborns for treatable disorders also constitute an infringement of the parent's liberty interest?¹³¹ Since there is a duty to treat a child when it is in the child's best interest to do so,¹³² would this not also include a duty to know whether treatment is necessary? Would a criminal law prohibiting therapeutic genetic alteration, whether in somatic or germ cells, constitute an infringement of the liberty of the person? The answer to these questions is unclear.

In the view of Chief Justice Dickson, the right to security of the person in the *Charter* constitutionalizes the principle of the inviolability of the human person. That is, the human body ought to be protected from interference by others. This right is not limited to the concept of physical control; it also protects against "stigmatization of the accused, loss of privacy, stress and anxiety resulting from a multitude of factors, including possible disruption of family, social life and work, legal costs . . ."¹³³ Thus, section 7 of the *Charter* would not only protect against the minimal physical intrusion involved in the mandatory taking of blood or tissue samples for genetic testing; it would also protect the psychological integrity of the person.¹³⁴ In the context of genetic medicine, section 7 may provide a safeguard against unwarranted interference with the autonomy and privacy of the person.

As stated earlier, Parliament could choose to infringe section 7 rights if it did so in a manner consistent with the principles of fundamental justice.¹³⁵ Determination of a possible infringement requires examination of the impugned legislation to see if, in its actual application and administrative and procedural structures, it is so manifestly unfair that it violates the principles of fundamental justice.¹³⁶ Thus, even if the rights under section 7 were found to have been violated, that infringement could be seen by the Court as being in accordance with the principles of fundamental justice.

131. See *Splicing Life*, *supra*, note 33 at 66ff and *Screening and Counseling*, *supra*, note 33.

132. Edward W. Keyserlingk, "Non-Treatment in the Best Interests of the Child: A Case Commentary of *Couture-Jacquet v. Montreal Children's Hospital*" (1987) 32 McGill L.J. 413.

133. *R. v. Morgentaler*, *supra*, note 129 at 55 citing Lamer J. in *Mills v. The Queen*, [1986] 1 S.C.R. 863. See also *Dion v. Attorney General of Canada*, [1986] D.L.Q. 353 (Que. Sup. Ct), where the indiscriminate taking of urine samples from prisoners for drug detection was seen as contrary to section 7 ("Le droit à l'intimité, à la discrétion et au secret des actes de la vie privée est une composante du droit à la sécurité de la personne") at 358. While urine testing may be difficult to justify in the absence of proof of reasonable grounds, blood tests may not be seen as unreasonable since they are "safe, painless and commonplace." George J. Annas, "Crack, Symbolism, and the Constitution" (1989) 19:3 *Hast. Cent. Rep.* 35.

134. In *R. v. Morgentaler*, *supra*, note 129, Dickson C.J. considered the concept of state-imposed psychological stress under the rubric of security of the person, whereas Wilson J. considered it under the rubric of liberty.

135. The principles of fundamental justice are "essential elements of a system for the administration of justice which is founded upon the belief in the dignity and worth of the human person and the rule of law." *Reference re Section 94(2) of the Motor Vehicle Act*, R.S.B.C. 1979, c. 288, [1985] 2 S.C.R. 486 at 512.

136. See *R. v. Jones*, *supra*, note 126.

This power of Parliament was confirmed in a case involving fingerprinting. The Supreme Court held that subjecting a person to obligatory fingerprinting with imprisonment as the sanction for failure to comply violated section 7. Nevertheless, the Court held that the infringement was in accordance with the principles of fundamental justice.¹³⁷ It reasoned that a person charged on reasonable and probable grounds with having committed a serious crime must expect a significant loss of personal privacy incidental to being taken into custody.¹³⁸

Cases such as the foregoing that concern traditional fingerprinting are relevant to DNA "fingerprinting."¹³⁹ That is the term applied to the laboratory analysis of the DNA of an individual. Each person's DNA is unique.¹⁴⁰ Because of this uniqueness, DNA analysis or "fingerprinting" can identify an individual with virtual certainty, if enough gene markers are examined and the techniques are properly done.¹⁴¹ These techniques have been applied to exclude or identify suspected criminals. Small samples of blood, sperm or even single strands of hair are sufficient to establish positive identity.¹⁴²

Extrapolating from cases involving traditional fingerprinting, the use of DNA fingerprinting may not be held to infringe the principles of fundamental justice in a criminal context, but may so infringe outside of that context. Two limitations may be placed on the use of such techniques or their reception into evidence in the criminal

137. *R. v. Beare*; *R. v. Higgins*, *supra*, note 130, in which fingerprinting was not considered to be an unreasonable search and seizure under section 8. See also Yves de Montigny, "La protection contre les fouilles, les perquisitions et les saisies abusives: un premier bilan" (1989) 49 R. du B. 53.

138. *R. v. Beare*; *R. v. Higgins*, *supra*, note 130 at 413.

139. Even though there is no Supreme Court decision on DNA typing, there is an abundance of case law on fingerprinting: see *R. v. Amway of Canada Ltd.*, [1986] 2 F.C. 312 (T.D.); *R. v. Therrien* (1982), 67 C.C.C. (2d) 31 (Ont. Co. Ct); *R. v. Esposito* (1985), 24 C.C.C. (3d) 88 (Ont. C.A.); *Re Jamieson and The Queen* (1982), 70 C.C.C. (2d) 430 (Que. Sup. Ct). It has not been interpreted as a violation of the privilege against self-incrimination under s. 11(c). On DNA fingerprinting, see also Gilles Létourneau and André A. Morin, "Technologie nouvelle et droit pénal" (1989) 49 R. du B. 821.

140. Motulsky, *supra*, note 13 at 2855. The exception is where a person has an identical twin.

141. M.C. King, "Genetic Testing of Identity and Relationship" (1989) 44:2 Am. J. Hum. Genet. 178; Roger Lewin, "DNA Typing on the Witness Stand" (1989) 244:4908 Science 1033; Alun Anderson, "New Technique on Trial" (1989) 339:6224 Nature 408 and Alun Anderson, "Judge Backs Technique" (1989) 340:6235 Nature 582 (recognition of using DNA for forensic testing as valid). Note, however, that in *State v. Castro*, 545 N.Y.S. 2d 985 (1989) (Bronx Cty), the evidence was excluded since the firm involved in testing failed to meet scientific standards. This technique of DNA typing is now being used in Canada. See Cristin Schmitz, "DNA Fingerprinting" (1989) 48:8 Lawyer's Weekly 1. See also *R. v. Parent* (1989), 65 A.R. 307 (Q.B.).

142. Banking of such data raises questions of civil liberties, since it is theoretically possible to identify everyone in the population from samples taken for other purposes, and such samples contain information about predisposition to disease: Jean L. Marx, "DNA Fingerprinting Takes the Witness Stand" (1988) 240:4859 Science 1616. These techniques have also been used to establish parenthood in cases involving alimentary obligations or immigration. It is worth mentioning that s. 11(c) of the *Charter* (privilege against incrimination) has been unsuccessfully raised with regard to traditional fingerprinting. See *supra*, note 139.

context. The first is proof of their reliability;¹⁴³ the second is whether such a practice "would bring the administration of justice into disrepute" under subsection 24(2) of the *Charter*.¹⁴⁴

IV. Unreasonable Search and Seizure

Section 8 of the *Charter* protects the person against unreasonable search and seizure. The Court has held that such protection must not be constrained by narrow legalistic classifications, based on notions of property and the like, that served to protect this fundamental human value in earlier times.¹⁴⁵ It also held that section 8 does not merely prohibit unreasonable search and seizure, and goes further to guarantee this right by providing an entitlement to be secure against unreasonable search and seizure.¹⁴⁶ Privacy, according to the Court, "is at the heart of liberty in a modern state" and its constitutional protection "has profound significance for the public order."¹⁴⁷

Therefore, the taking of a blood sample from an unconscious patient was seen by the Court as a violation of the sanctity of a person's body and as a serious affront to human dignity.¹⁴⁸ Furthermore, even where there is no "search" in the physical sense of taking a blood or tissue sample, "the use of a person's body without his consent to obtain information about him, invades an area of personal privacy essential to the maintenance of his human dignity."¹⁴⁹ Thus, even where consent to the taking of a sample or the participation in a test is obtained, the Court was clear in its opinion that the information derived from it should be restricted to the medical purposes for which it was given. Indeed, in the context of medical care, the Court held that "[t]his is obviously necessary if one considers the vulnerability of the individual in such circumstances. He is forced to reveal information of a most intimate character and to

143. The *Castro* case, *supra*, note 141, failed on this point, the prosecution having relied on tests that had not met scientific standards.

144. See *R. v. Dymnt*, [1988] 2 S.C.R. 417.

145. See *Hunter v. Southam Inc.*, [1984] 2 S.C.R. 145 at 160, which held that the purpose of s. 8 "is . . . to protect individuals from unjustified state intrusions upon their privacy."

146. *Minister of National Revenue v. Kruger Inc.*, [1984] 2 F.C. 535 (C.A.).

147. *R. v. Dymnt*, *supra*, note 144 at 427 referring to Alan Westin's *Privacy and Freedom*.

Grounded in man's physical and moral autonomy, privacy is essential for the well-being of the individual. For this reason alone, it is worthy of constitutional protection, but it also has profound significance for the public order.

148. *R. v. Pohoretsky*, [1987] 1 S.C.R. 945, involved a doctor who took a blood sample at the request of a police officer from a patient who was in an incoherent and delirious state.

149. *R. v. Dymnt*, *supra*, note 144 at 431-32.

permit invasions of his body if he is to protect his life or health.”¹⁵⁰ The Court went further in requiring pressing necessity or prior patient authorization for the taking of blood or other bodily substances for secondary purposes.¹⁵¹ The privacy of the person, according to the Court, transcends the physical, and the seizure in question constituted a violation of human dignity.¹⁵² This holding, although in the criminal context, is also important in the present context.

Genetic testing, and the banking and use of DNA and the genetic information it contains, could be done without the knowledge of a person, where, for example, a blood sample was obtained for other purposes. This could be a violation of section 8 of the *Charter*.

The need for prior authorization for any uses of genetic materials or information is an important step in ensuring a respect for human dignity in the medical context.¹⁵³ The difficulty is that, unlike ordinary medical treatment or diagnosis, genetic testing often involves families — sometimes extended families. Thus, testing may extend over time and over generations. If the original consent is to be respected, family members or the original participant must be contacted for authorization where use is to be made of samples, which use was not within the scope of the original consent.¹⁵⁴ We will see in the following chapters that the maintenance of choice and “the trust and confidence of the public in the administration of medical facilities”¹⁵⁵ depends on a new social construct, and on the elaboration of the concept of genetic justice.

V. Equal Treatment and Freedom from Discrimination

The remaining *Charter* right meriting discussion in relation to genetic heritage is the right to equal treatment and the prevention of discrimination. The categories under which discrimination is prohibited include race, national or ethnic origin, colour, religion, sex, age and mental or physical disability. But could one refuse to grant a right or a privilege to some individuals on the basis of their genome?

150. *Ibid.* at 433. The Court also noted at 439 that “the trust and confidence of the public in the administration of medical facilities would be seriously taxed if an easy and informal flow of information, and particularly of bodily substances from hospitals to the police, were allowed.” This trust is crucial for public participation in preventive medicine.

151. *Ibid.* at 430, 436. See also *R. v. Legere* (1989), 5 W.C.B. (2d) 384 (N.B.C.A.).

152. *R. v. Dymont*, *supra*, note 144 at 439. The Court also referred for guidance to the report of the Law Reform Commission of Canada, *Obtaining Forensic Evidence*, Report 25 (Ottawa: The Commission, 1985) at 1.

153. See Knoppers and Laberge, *supra*, note 91 at 1024.

154. *Ibid.* at 1026.

155. *R. v. Dymont*, *supra*, note 144 at 439.

The right to equality before and under the law, according to the Supreme Court, also includes any discriminatory impact that a law may have.¹⁵⁶ Thus, distinctions founded on the personal characteristics of an individual or a group, which would have the effect of imposing obligations or disadvantages not imposed on others or which would restrict access to benefits accorded to others, would be considered discriminatory. Even if the effect of being considered and treated as genetically different would not at first glance fall into one of the prohibited categories, the Court envisaged the possibility of enlarging those categories of protected minorities under section 15 of the *Charter*.¹⁵⁷ Thus, theoretically, the genetically handicapped or disabled could become an additional category.

The Supreme Court saw the enumerated categories found in section 15 as characteristics inherent in the person and not acquired by his or her choice, merit or capacity. Thus, an individual would be protected from discrimination based on that individual's genome, irrespective of whether one labelled it as race, ethnic origin or handicap. Consequently, legislation mandating genetic testing could be perceived as discriminatory where it deliberately or incidentally identifies certain racial or ethnic groups carrying certain genetic traits as the basis for differential treatment. The compulsory genetic testing of pregnant women could also run afoul of section 15. If genetic testing were to be done to determine eligibility for employment¹⁵⁸ or other benefits in a *Charter*-regulated industry, or if it affected the right to marry or procreate, such state conduct could be seen as discrimination on the grounds of physical or mental disability.

However, the inclusion of genetic handicap in the general notion of handicap is problematic. It might mean that being genetically different is equivalent to having a disability because the distinction between a "difference" and a "handicap" is not always clear. Another view is preferable, namely, that we are all genetically equal because we all have certain genetic differences from one another. Thus, genetic difference could be seen as the foundation for a new social contract based on that genetic equality.¹⁵⁹

156. Prior to *Andrews v. Law Society of British Columbia*, [1989] 1 S.C.R. 143, "a similarly situated" test was the basis of most equality cases. Others tended to accept an "invidious discrimination" test. Both these stands were rejected in *Andrews*. The first was held to be seriously deficient on account of its formalism and failure to consider the nature of the law. The second was held to confuse s. 15(1) and (2). Thus, it was sufficient for the complainant to prove a discriminatory distinction causing a "prejudice or disadvantage."

157. *Ibid.*

158. Edith F. Canter, "Employment Discrimination Implications of Genetic Screening in the Workplace under Title VII and the Rehabilitation Act" (1984-85) 10 Am. J.L. Med. 323. See also Karim Benyekhlief, "Réflexions sur la légalité des tests de dépistage de drogues dans l'emploi" (1988) 48 R. du B. 315.

159. See below, Chapter Six.

VI. Reasonable Limits

If legislation with regard to genetic testing were proposed, would it be considered reasonable and justifiable in a free and democratic society? According to section 1 of the *Charter*, legislation violating a *Charter* right will survive constitutional challenge if the reasonable limits prescribed therein "can be demonstrably justified in a free and democratic society."¹⁶⁰ The burden of proof falls on the legislature responsible for the impugned legislation.

The Supreme Court has ruled that not only must the limit on a protected *Charter* right be demonstrably justifiable, but also the means used in the exercise of that limit must be reasonable.¹⁶¹ The objective of any legislation or a provision therein must be of "sufficient importance to warrant overriding a constitutionally protected right or freedom."¹⁶² The "reasonableness" test ensures that the legislative means are proportional to the legislative ends.¹⁶³ The means chosen should be rational and fair, not arbitrary. They should impair as little as possible the right or freedom under consideration, and the effect of the limitation should not be disproportionate to the objective sought.¹⁶⁴ Finally, the Court reiterated that the values of a free and democratic society include "respect for the inherent dignity of the human person, commitment to social justice and equality, accommodation of a wide variety of beliefs, respect for cultural and group identity, and faith in social and political institutions which enhance the participation of individuals and groups in society."¹⁶⁵

It is doubtful that any form of compulsory genetic screening or testing could survive this final test of section 1.

VII. Conclusion

Charter protection is limited in its scope and application. The interpretation of *Charter* rights by the Supreme Court of Canada suggests that freedom of genetic choice may be protected under the fundamental rights of: freedom of association and

160. Such proof may be derived from social science data, reports for Royal Commissions and Parliamentary Committees and laws in other free and democratic societies as evidenced in treatises on comparative law and in international covenants. This places a responsibility on the opposing party to rebut such evidence by showing that it is "neither cogent nor persuasive, or that the Crown has failed to demonstrate the consequences of imposing or not imposing the limit." Morris Manning, "Proof of Facts in Constitutional Cases" in Gérald-A. Beaudoin, ed., *Charter Cases 1986-87* (Cowansville, Que.: Yvon Blais, 1987) 271 at 284.

161. *R. v. Oakes*, [1986] 1 S.C.R. 103.

162. *R. v. Big M. Drug Mart Ltd.*, *supra*, note 124 at 352.

163. *R. v. Oakes*, *supra*, note 161 at 139-40.

164. *R. v. Edwards Books*, [1986] 2 S.C.R. 713.

165. *R. v. Oakes*, *supra*, note 161 at 136.

conscience and religion; life, liberty and security of the person; freedom from unreasonable search and seizure; and the right to equality. These rights could be a powerful tool to ensure that the inherent dignity of the person will be respected in the area of human genetics.

Geneticists have, through self-regulation, taken steps in that direction. Screening is only acceptable where the condition is serious and the testing accurate. Moreover, therapy or effective intervention must be available and the cost of screening must be commensurate with the gains to be achieved.¹⁶⁶ As human genetics expands to include predictive genetics for a greater number of diseases and people, do the general legal or scientific safeguards described in this chapter suffice? What serious, identifiable and treatable diseases could be screened for in a cost-effective manner so as not to infringe constitutional rights and freedoms?¹⁶⁷

We have argued that, at present, the Canadian *Charter* may offer the freedom of choice necessary to safeguard the concept of human dignity on which the *Charter* is founded. However, considering current social prejudices surrounding disease, can we rely on these general *Charter* rights to safeguard the freedom of genetic choice?

The knowledge that the new genetics is providing gives rise to difficult choices. The ability to identify diseases that are not yet treatable, the expansion of carrier testing to include new diseases such as cystic fibrosis, the banking of DNA for future research (on as yet unidentified individuals for as yet unidentified diseases) and the identification of rare diseases with doubtful cost-benefit ratios will force the scientific community to re-evaluate the traditional criteria for screening and testing.¹⁶⁸ It may force us to go beyond relying on the *Charter* rights described. Perhaps we should ask, What do we as a society consider to be genetically "normal"? and then consider expanding or restricting legislative intervention in genetic medicine.

166. National Academy of Science, *Genetic Screening: Programs, Principles, and Research* (Washington, D.C.: U.S. Government Printing Office, 1975) confirmed in the President's Commission Reports, *supra*, note 33. Considering the state of knowledge in 1976, the Academy saw no relationship between compulsory public health measures for communicable diseases and those for genetic diseases. See also Robert Steinbrook, "In California, Voluntary Mass Prenatal Screening" (1986) 16:5 *Hast. Cent. Rep.* 5.

167. At present only screening in newborns for PKU and other treatable metabolic disorders meets these criteria. Even then, screening in Canada is presently not subject to legislative sanction. The general common law rules of informed consent apply.

168. Kathleen Nolan and Sara Swenson, "New Tools, New Dilemmas: Genetic Frontiers" (1988) 18:5 *Hast. Cent. Rep.* 40, argue that the four traditional criteria for good screening (serious disease; accurate test; treatment or meaningful intervention; reasonable cost) are no longer clear in the context of modern genetics. See Bartha M. Knoppers and Claude M. Laberge, "Genetic Screening: From Newborns to DNA Typing" in Bartha M. Knoppers and Claude M. Laberge, eds, *Genetic Screening: From Newborns to DNA Typing* (Amsterdam: Excerpta Medicine, 1990) 379.

CHAPTER FIVE

Genetic ‘Ab-normality’

I. Introduction

Differing views of human nature may lead to differing social choices; this is particularly pertinent to human genetics. Conversely, differing views of human genetics may lead to differing views of human nature and to the limitation or expansion of social choices. If we see the gene as determinant of the person, then the knowledge that someone carries a particular genetic trait acquires, in the eyes of some, a fatalistic perspective. In this situation, choices will centre around the elimination or manipulation of the gene since the person, and the person's disease, is seen as being biologically predetermined. If we view the random diversity of genetic characteristics as natural and as the essence of humanity, we may resist genetic intervention regardless of the reasons for it. If, on the other hand, we see the human being as determined by social, environmental and historical forces, a knowledge of human genetics may help to combat or to mould those forces according to the given political ideology at a given time.

In this chapter, we will survey the notions of genetic determinism, naturalism, discrimination and perfectionism. We will also point out some of the legal implications that may arise from the social choices made with respect to ‘normal’ or ‘healthy’ genomes.

II. Genetic Determinism

Biological or genetic determinism is the belief that “all human behavior — hence all human society — is governed by a chain of determinants that runs from the gene to the individual to the sum of the behaviors of all individuals. The determinists would have it, then, that human nature is fixed by our genes.”¹⁶⁹ Thus, it is a reductionist view that defines the nature of humankind in terms of its biology or genes.

169. Richard C. Lewontin, Steven Rose and Leon J. Kamin, *Not in Our Genes* (New York: Pantheon Books, 1984) at 6.

In their book, *Not in Our Genes*, Lewontin and his colleagues trace the history of genetic determinism.¹⁷⁰ The dismantling of the living organism began with a demonstration that physical laws applied to the animate as well as the inanimate, and the two were assumed to be similarly constituted. However, there was a paradox. If the animate and the inanimate were similarly constituted, it ought to have been possible to create life from its inanimate components. Yet, Pasteur had shown that life could only emerge from life.

A view of how life emerged was presented in the work of Charles Darwin. He theorized that living things evolved through time by a process of natural selection acting on an over-abundance of offspring, each with varying degrees of adaptability. This dimension of time allowed Darwin to speculate that the first step in this progression was the formation of life from non-living substances. Thus, materialist biology replaced God with science as the determinant of the social order.¹⁷¹

What was left unexplained by Darwin's theory was how the inherited variation within a population, upon which selective forces acted, was maintained. Mendel's theory of the gene as the unit of inheritance provided the answer. A description of how information transfer occurred between the gene and the cell products awaited the work of Watson and Crick who, in the 1950s, elucidated the genetic code. Thus, the working of the cell in producing proteins from mRNA, and from DNA, came to be seen as an assembly line and the organism came to be seen as "merely DNA's way of making another DNA molecule."¹⁷²

Shortly after Darwin developed his theory of evolution, Galton attempted to reduce behaviour to quantifiable norms and to attribute its origin to ancestral inheritance.¹⁷³ His erroneous view that mental illness and criminality were largely biologically determined fuelled the eugenics movement that he founded. That movement gave rise to restrictive immigration policies, sterilization programs and, eventually, the extermination of those considered by the Nazis to be undesirable.

Unfortunately, the horrors of the Holocaust did not make genetic determinism go away. It re-emerged as an explanation for social phenomena with the publication of Arthur Jensen's treatise on IQ in which he argued, in a way that has since been shown to be flawed,¹⁷⁴ that IQ differences between the races could be largely explained by genetic differences. This was followed by the work of E.O. Wilson, who captured the attention of the popular press with his socio-biological theory of human nature. His

170. *Ibid.*, Chapter 3 at 37.

171. *Ibid.* at 51

172. *Ibid.* at 58.

173. *Ibid.* at 56.

174. *Ibid.* at 118.

proposal, which has been systematically and thoroughly criticized,¹⁷⁵ was that many human characteristics, such as tribalism, xenophobia and altruism, are also found in animals. He proposed that, like physical characteristics, these behavioural characteristics have been moulded by evolutionary forces. Thus, in this view, the characteristics of society as we know it are predictable, if not inevitable.

Lewontin and his colleagues, on the other hand, argued for a broad vision of the complexity of the forces that shape us as individuals and as a society — one that would give meaning to freedom:

What characterizes human development and actions is that they are the consequence of an immense array of interacting and intersecting causes. Our actions are not at random or independent with respect to the totality of those causes as an intersecting system, for we are material beings in a causal world. But to the extent that they are free, our actions are independent of any one or even a small subset of those multiple paths of causation: that is the precise meaning of freedom in a causal world.

...

For biological determinists we are unfree because our lives are strongly constrained by a relatively small number of internal causes, the genes for specific behaviors or for predisposition to these behaviors. But this misses the essence of the difference between human biology and that of other organisms. Our brains, hands, and tongues have made us independent of many single major features of the external world. Our biology has made us into creatures who are constantly re-creating our own psychic and material environments, and whose individual lives are the outcomes of an extraordinary multiplicity of intersecting causal pathways. Thus, it is our biology that makes us free.¹⁷⁶

Another opponent of the reductionist view of man is Albert Jacquard, who attempted to establish the specificity of the human person. While recognizing the interaction and mutual influence of the gene with the environment in general, he introduced a particular environmental influence, that of a specific culture in a given society. This cultural influence could be random or even unknown in its effect. According to Jacquard, the dialectic of all these factors demonstrated individual genetic complexity. In that complexity lay the possibility to move from *animalité* based on biological determinism to *humanité*. *Humanité* was based on the belief of an active contribution by each person to the further construction and complexity of the human person, individually and collectively.¹⁷⁷ Thus, each person is an active agent in the definition of what is and what will be the human person and society. How the individual acts on genetic knowledge will, in turn, be influenced by the collective concept of normality.

Despite the strong criticism that has been levelled at biological determinism, it seems to underlie certain proposals to justify budget cuts for welfare and education, to

175. *Ibid.*, Chapter 9 at 233, refutes Wilson's theory as to its description of human nature, as to the characters he chose to describe human nature being a consequence of gene action, and as to his attempt to show that these characters were established by the evolutionary forces of natural selection.

176. *Ibid.* at 289-90. See also François Jacob, *La logique du vivant: une histoire de l'hérédité* (Paris: Gallimard, 1970) and François Jacob, *The Statue Within* (New York: Basic Books, 1988).

177. Albert Jacquard, *L'héritage de la liberté: de l'animalité à l'humanité* (Paris: Seuil, 1986) at 178-79.

support restrictive immigration policies and to prevent equality in the workplace.¹⁷⁸ According to this position, the existing hierarchy is natural and inevitable, since it is based on intrinsic hereditary factors. All the more reason to appeal to a system of justice and political order to redress inequalities.¹⁷⁹

This cursory overview of genetic determinism, while in no way philosophically complete, illustrates the relationship between scientific knowledge and our understanding of human origins and of human nature. It also highlights the possible use of deterministic biology in the political process. We must be aware of this in finding solutions to the problems raised by advances in human genetics.

One author points out, for example, that while geneticists may appreciate that the environment as well as genes play a role in expression, "in the popular mind genes are widely perceived as emissaries of biological destiny."¹⁸⁰ As a result, "probes may acquire a misleading status in our medical armamentarium as indicators of a new kind of biological determinism."¹⁸¹ The foregoing emphasizes the great need for education in this area. The human person is neither programmed nor programmable. Indeed, the genetic composition of any person is changeable.¹⁸²

III. Genetic Naturalism

Genetic determinists would have it that we cannot change our social condition because it is fixed by our genes. Genetic naturalists argue that our genetic constitution is natural, that this naturalness determines our humanity and that, therefore, we should not tamper with it.

The naturalist view was expressed in the Enquete Commission.¹⁸³ It said: "the humanity of human beings rests at its core on natural development The dignity of human beings is based essentially on their being born and on the naturalness of their origins."¹⁸⁴ In its view, an essential element of this naturalness was that we are a "product of chance," and that this "secures the independence of human beings from each other." Thus, in its view, any manipulation that detracts from this chance event would be "incompatible with the essence of a free person."¹⁸⁵ This view led the

178. Lewontin, Rose and Kamin, *supra*, note 169.

179. *Ibid.*

180. Lappé, *supra*, note 7 at 8.

181. *Ibid.* at 10.

182. David Suzuki and Peter Knudtson, *Genethics: The Ethics of Engineering Life* (Toronto: Stoddart, 1988).

183. Enquete Commission, *supra*, note 39. See also Conseil d'État, *supra*, note 37; Edelman and Hermitte, *supra*, note 52; Commission d'experts, *supra*, note 38.

184. Enquete Commission, *supra*, note 39 at 257.

185. *Ibid.*

Enquete Commission to recommend a ban on any gene technology that would interfere with the human germ line.

This and other aspects of the Enquete Commission were severely criticized by Hans-Martin Sass.¹⁸⁶ He points out that we are not "products of chance." Rather, there are many ways in which we manipulate our lives socially and culturally. Others have agreed that such an approach would view "randomness" as being the sole source of our uniqueness and thus deserving protection as immutable and untouchable. This fear of the elimination of chance, of the stifling of the authenticity of the human person, is based on the erroneous view that we are fundamentally no more than our genetic material.¹⁸⁷ That is, genetic naturalism, like genetic determinism, is a reductionist view of humankind.

Boone suggests that what is natural "should be based on some human conception of what is natural, not on a naturalistic definition of what is human."¹⁸⁸ Furthermore, Sass argues that even if we were to accept a naturalistic view of human nature we may ask: "Are humans naturally biological beings or manipulating beings; . . . ?"¹⁸⁹ — that is, What is the nature of humans: to protect or to manipulate their nature? "The issue is not whether or not human dignity allows germ-line manipulation, but which forms of germ-line manipulations or any other manipulations are morally acceptable and which are not."¹⁹⁰

Thus, there are two issues. The first is the nature of humanity and human dignity. The second is the changes that might be morally permissible if we reject that humans must remain unalterable, natural biological beings.

We have seen that the concept of human dignity underlies international law and the *Canadian Charter of Rights and Freedoms*.¹⁹¹ It is a term that is interpreted rather than defined. However, "[w]ithout a reasonably clear general idea of its meaning, we cannot easily reject a specious use of the concept."¹⁹² Sass suggests that what human dignity "means in concrete situations has to be analyzed and assessed in moral argumentation, in public debate, by the educated citizen as the prime moral agent, by professional organizations, also by regulators and legislators, but it cannot be pre-determined by . . . referring to obscure natural law concepts."¹⁹³

186. *Supra*, note 39.

187. Wolfgang Schirmacher, "Homo Generator: The Challenge of Gene Technology" in Paul T. Durbin, ed., *Technology and Responsibility* (Dordrecht: D. Reidel, 1987) 203.

188. Boone, *supra*, note 2 at 11.

189. *Supra*, note 39 at 270.

190. *Ibid.* at 269.

191. Above, Chapters Three and Four.

192. Schachter, *supra*, note 116 at 849.

193. Sass, *supra*, note 39 at 272.

Respect for the dignity of man has always been seen as one of the few absolute rights¹⁹⁴ and the assertion and proclamation of human rights themselves as a refusal to submit to humankind's interpretations of the laws of nature.¹⁹⁵ It would be paradoxical, therefore, to limit respect for human dignity to a biological, naturalistic conception of the human person.¹⁹⁶

The second issue concerns the decision as to when manipulation might be morally permissible, were we to reject genetic naturalism. The natural law position closes the door on frightening scenarios of unethical manipulations by prohibiting outright all interventions affecting the gene. But, the question is "not whether we should alter the human genetic code, but with which consciousness we do it."¹⁹⁷ In response to the challenge of the new genetics, one author suggests that in deciding what is permissible in science we must adopt the principle of "moral imagination" to determine what the consequences of our actions might be.¹⁹⁸

IV. Genetic Discrimination

Discrimination as to genotype can be seen as either a means of informing one's personal decisions, or as a means of imposing the decisions of others.¹⁹⁹ We will look at three areas in which genetic disposition may be used to discriminate against the individual: testing in the workplace, testing for access to insurance and testing for reproduction.

A. Workplace Testing

The purposes of genetic screening in the workplace include the determination of the cause of an illness (for example, to what degree it is genetic or environmental in origin), and the prevention of illness by the detection of genetic susceptibility. This could be of benefit to both the employee and the employer. Since genetic information demonstrates individuality, it can provide the employee or the potential employee with information to make occupational, environmental or life-style choices that are in his or

194. Mireille Delmas-Marty, "Droits de l'homme et conditions de validité d'un droit de l'expérimentation humaine" at 155 and Patrick Verspieren, "Le respect de la dignité humaine" at 147 in Fondation Marangopoulos pour les Droits de l'Homme, *Expérimentation biomédicale et Droits de l'Homme* (Paris: P.U.F., 1988).

195. Delmas-Marty, *supra*, note 194 at 155.

196. Laberge, *supra*, note 9 at 231.

197. Schirmacher, *supra*, note 187 at 214.

198. Daniel Callahan, "Ethical Responsibility in Science in the Face of Uncertain Consequences" (1976) 265 *Annals N.Y. Acad. Sci.* 1.

199. Suzuki and Knudson, *supra*, note 182, Chapter 7 at 160.

her own interests. Such information also provides the employer who has access to it with the power to control or exclude the person tested. At the same time, it gives the employer a greater responsibility for employee health and safety, based on that information.²⁰⁰

Genetic screening may be lawful if directly related to qualifications for doing a task or if necessary for employee safety. It could be argued, however, that refusal or termination of employment should only be permitted on the basis of the employee's current capabilities and not on predicted future incapacities.²⁰¹

Furthermore, while the employee should have a right to any information obtained about himself or herself, workplace testing poses a special problem with regard to medical confidentiality. The employer is privy to information that is usually confined to the physician-patient relationship. The potential for breaches of confidentiality may be of special concern where personnel data are computerized.²⁰²

In 1982, the United States Office of Technology Assessment conducted a nationwide survey on genetic testing in the workplace. Its report²⁰³ revealed that such testing, used by many employers, may be scientifically unfounded. This was the case, for example, with sickle cell testing.²⁰⁴ Sickle cell anaemia is a life-threatening autosomal recessive disorder with a high frequency among blacks. Those who carry only one of the two mutant alleles are said to have the sickle cell trait. Even though there was, and is, no evidence that having the trait affects work performance, blacks were often screened for it and were excluded from some occupations on that basis.

It could be asked whether protection against discrimination on the basis of mental or physical disability as provided by the *Charter*,²⁰⁵ or by provincial human rights codes,²⁰⁶ would be broad enough to include genetic discrimination.

While awaiting the diffusion of genetic education at all levels of society, the balance to be struck between workplace safety, individual rights and employer or public

200. See Bartha M. Knoppers "Genetic Screening and Genetic Information in the Workplace" (Address to the American Society of Human Genetics, October 1986) [unpublished].

201. *Ibid.* The author argues that employers should only be able to require genetic screening when the probability of risk of disease can be measured effectively to determine actual job fitness.

202. *Ibid.* See especially Thomas H. Murray, "Warning: Screening Workers for Genetic Risk" (1983) 13:1 *Hast. Cent. Rep.* 5.

203. OTA, *The Role of Genetic Testing in the Prevention of Occupational Disease* (Washington, D.C.: OTA, 1983). The OTA is currently updating its assessment.

204. See also Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (New York: Alfred A. Knopf, 1985) at 257, 278, who demonstrates that voluntary and congressional-supported testing for Tay-Sachs disease for Ashkenazic Jews was much more successful and less stigmatizing than testing mandated for sickle cell disease.

205. *Canadian Charter of Rights and Freedoms*, *supra*, note 6, s. 15. See above, Chapter Four.

206. *E.g.*, *Charter of Human Rights and Freedoms*, *supra*, note 76, s. 10.

health care costs is a delicate one. In the absence of widespread genetic education, we may need a specific legal prohibition on genetic discrimination.²⁰⁷

B. Insurance Testing

The issue of genetic testing as a prerequisite for insurance raises similar concerns. The Canadian health care system, with its universal coverage of the costs of illness, gives greater protection to Canadians than does the American system to their counterparts.²⁰⁸ Nonetheless, private disability insurance, life insurance policies and employer-sponsored programs share similar problems with the United States of rating persons "at risk." Parallels could be made with current insurance practices on HIV seropositivity where high-risk individuals pay a higher rate or may be denied coverage altogether. Unlike the situation in employment testing, testing for insurance usually does not directly benefit insurance applicants; moreover, knowledge derived from such testing could be just as easily acquired through one's personal physician without the above consequences.²⁰⁹

For personal policies, the insurance company must be privy to sensitive health information concerning an individual. But test reliability and validity, as well as the unjustifiable discriminatory exclusion of those persons with a high risk of disease, are factors to be considered in the development of future legislative policies.²¹⁰ The very nature of private insurance legitimates discrimination. However, a basic disability or life insurance for all applicants with "no questions asked" could provide minimum coverage to everyone and avoid problems of discrimination. Additional coverage could be dependent on an agreement by the applicant to be tested for genetic disorders.

C. Reproductive Testing

Certain legal and canonic rules have always imposed restrictions on consanguineous marriages (that is, between genetically related individuals). Nevertheless, genetic screening is not a legal requirement for marriage.²¹¹ Unlike blood testing for rhesus

207. See Science Council of Canada, *supra*, note 34.

208. A recent OTA Report, *Medical Testing and Health Insurance*, (Washington, D.C.: OTA, 1988) at 7, revealed that in the U.S., 20 per cent of individuals and 15 per cent of group members were rated as "substandard" and issued health insurance policies at higher rates while 8 per cent of individuals and 10 per cent of small group applications were judged uninsurable and denied coverage.

209. L.D. Jones, "The Use of Genetic Information in Evaluating Insurability" (Address to the American Society of Human Genetics, October 1986) [unpublished].

210. Knoppers, *supra*, note 200.

211. Four American states mandate pre-marital genetic screening. See Andrews, *supra*, note 8 at 233. This is not to be confused with the situation in those countries or states that do ordinary blood testing (rhesus, toxoplasmosis or rubella titre, infectious diseases, etc.) before the issuance of a licence.

compatibility, which is generally mentioned to prospective couples by their physician, other genetic testing is not.²¹² However, as family linkage studies develop and expand, and as individuals become genetically informed and sensitized, voluntary recourse to genetic testing before marriage or reproduction will be more frequent. Yet, even for certain populations at identifiably high risk,²¹³ the state should have to justify mandatory screening that interferes with such a personal decision as marriage or procreation.

In Chapter Three, we discussed a proposal by the Parliamentary Assembly of the Council of Europe to legislate a right to an unaltered genetic heritage. A genome could be considered "altered" if it would result in one of a list of serious illnesses. It was suggested that the right of an individual with such an "altered" genome to have children might be tied to the individual's agreeing to undergo genetic engineering.²¹⁴ Available and accessible genetic testing would be more effective and less intrusive routes of health policy, by allowing carriers to make their own choices with respect to such risks, that is, whether to marry, have children and use prenatal testing where available.

In the field of reproductive technologies, physicians are advised to offer donor gametes or embryos to couples at genetic risk or to follow up those persons (or their progeny) found to be at genetic risk.²¹⁵ Furthermore, the risk of transmitting serious genetic disease is generally accepted as one of the criteria for the use of reproductive technology.²¹⁶ Will the availability of the technology and the choices for the selection of "healthy" gametes or embryos bring us one step closer to striving for genetic perfectionism?

212. See, however, the recent Illinois legislation, *An Act (Public Act 86-884, Laws 1989) in relation to sexually transmitted diseases and inherited metabolic diseases, amending named Acts*, approved 11 September 1989 as cited in (1990) 41:1 Int. Dig. Hlth Leg. 57. S. 204 reads as follows: "The country clerk shall distribute . . . to all persons applying for a marriage license, a brochure . . . concerning sexually transmitted diseases and inherited metabolic diseases."

213. During to the high incidence of thalassaemia in Cyprus, the Greek Orthodox Church requires all couples intending to marry to be tested for carrier status. (Personal Communication, Council of Europe, Mrs. Nafsika Kronidou, Cyprus, 1989).

214. *Supra*, note 89ff and accompanying text; see also Kevles, *supra*, note 204 at 277 citing Paul Ramsey: "The freedom of parenthood is a freedom to good parentage, not a license to produce seriously defective individuals to bear their own burdens." Kevles also notes that the Chicago Bar Association is in favour of obligatory pre-marital genetic screening and therapy, where available.

215. Bartha M. Knoppers, "L'arbitrage du médecin face aux normes régissant la fécondation 'in vitro'" in Christian Byk, ed., *Artificial Procreation: The Present State of Ethics and Law* (Lyon: Lacassagne, 1989) 49.

216. *Ibid.*

V. Genetic Perfectionism

The most common fear is that of striving for genetic perfectionism.²¹⁷ The policy of genocide for the purpose of attaining "racial purity" has already been mentioned.²¹⁸ This erroneous equation between race or nations and genetic bases reached its nadir with the Nazi policies of World War II. Considering the associations between the Holocaust and eugenics, it was hoped that the eugenic ideal would be put to rest after that war.

In the United States during the 1970s, seven states passed laws mandating the screening of the black population for the sickle cell trait. In at least five of those states, marriage licences were denied to those who refused to participate.²¹⁹ A decade later, a sperm bank offering gametes of "superior" quality was set up in California.²²⁰ And in Canada, as in the United States, some laws making genetic sterilization of the mentally disordered compulsory were not repealed until the 1970s.²²¹

State eugenic policies are often disguised under the language of common good, cost-benefit or public health. The availability of amniocentesis for the prenatal diagnosis of disorders such as Down syndrome, and the inclusion of eugenic clauses in the abortion statutes of some countries,²²² now make these choices as to what is "normal" more a part of personal decision making. As more and more genetic conditions of less and less severity are detectable prenatally, there may be greater social pressure in reproductive decision making. This may detract from research seeking appropriate therapy²²³ or from the improvement in the social conditions of the "less than genetically perfect." Should control be exercised over such choices? If so, by whom?

There are two types of eugenics, negative and positive. Negative eugenics aims to decrease the frequency of disadvantageous genes, and positive eugenics aims to increase the frequency of advantageous genes.

217. Boone, *supra*, note 2; see also Lappé, *supra*, note 7; J. Frézal, "Les problèmes éthiques en génétique humaine" (1985) 104 *Louvain Medical* 38.

218. See also Raphaël Lemkin, *Axis Rule in Occupied Europe* (Washington, D.C.: Carnegie Endowment for International Peace, 1944), Chapter 9, "Genocide," at 79. Lemkin coined the term in this germinal work and tirelessly fought to have the concept both recognized by the United Nations and ratified by more than 100 nations (*Convention on the Prevention and Punishment of the Crime of Genocide* (1948) 78 U.N.T.S. 277).

219. See Holtzman, *supra*, note 8 at 219.

220. See Kevles, *supra*, note 204 at 262-63. See also Gwen Terrenoire, "Conseil génétique et eugénisme: le passé du conseil génétique aux États-Unis" (1986) 11 *Cahiers Science, technologie et société* (Éthique et Biologie) Paris, Éd. du C.N.R.S. 171.

221. See, e.g., *The Sexual Sterilization Act*, S.A. 1928, c. 37, and *Sexual Sterilization Act*, S.B.C. 1933, c. 59, repealed in the early 1970s.

222. See *Crimes against the Foetus*, *supra*, note 113 at 69.

223. Lappé, *supra*, note 7 at 9; see also Holtzman, *supra*, note 40 at 628.

When a genetic disorder is not completely treatable,²²⁴ the approach has been to counsel those individuals who are at risk. They could then exercise informed procreative choice. This is negative eugenics.²²⁵ At the same time, advanced technology may also allow embryo selection (or, less likely, germ-line selection) aimed at increasing the transmission of genes considered advantageous. This is positive eugenics.

There are, however, limits as to the effectiveness of either positive or negative eugenics in altering the gene pool, which is the ultimate aim of eugenics. The most forceful restraint on the revival of eugenics is nature itself,²²⁶ because only a fraction of human traits and disorders is traceable to single genes, for or against which selection might be made. The common familial disorders have a polygenic basis. This limitation constitutes a balm to the exaggerated fears often accompanying debates on human genetics.²²⁷ Nevertheless, in addition to being confronted with choices of normality in everyday life, we now face choices as to what we will consider genetically "normal" for future generations.

One area where policies concerning genetic selection or perfectionism have to be formulated immediately is that of reproductive technologies. These technologies provide usable and accessible human genetic material in the form of gametes (egg or sperm) and human embryos. In conformity with all of the international reports published to date,²²⁸ a recent Working Paper of the Law Reform Commission of Canada suggests prohibiting the more extreme forms of genetic experimentation on the human embryo.²²⁹ Similarly, the Parliamentary Assembly of the Council of Europe recently recommended limiting genetic experimentation to therapeutic purposes. Thus, the assembly would prohibit the more extreme possibilities of genetic engineering such as the cloning of individuals and non-therapeutic genetic manipulation for the purpose of sex or race

224. E.g., PKU, which can be detected by newborn screening and treated with a low protein diet. Nevertheless, the burden so incurred still influences some parents to seek prenatal diagnosis.

225. The term "eugenics" is generally avoided in referring to prenatal diagnosis and the emphasis is placed on its permitting couples at risk to have normal children.

226. Kevles, *supra*, note 204 at 289.

227. *Ibid.*; Boone, *supra*, note 2.

228. See generally Knoppers, *Reproductive Technology*, *supra*, note 89 at 336-58 and the follow-up report. We have argued that the existing international human rights texts are insufficient and lack the specificity necessary to protect the human person in the light of scientific advances. However, while awaiting legislative intervention, the interpretation of these legal texts on human experimentation could be expanded. See especially Fondation Marangopoulos pour les Droits de l'Homme, *supra*, note 194 and Law Reform Commission of Canada, *Biomedical Experimentation Involving Human Subjects*, Working Paper 61 (Ottawa: The Commission, 1989).

229. See *Biomedical Experimentation Involving Human Subjects*, *supra*, note 228 (which did not cover somatic or germ-cell therapy or alteration); *Crimes against the Foetus*, *supra*, note 113 at 60.

selection: "human embryos and fetuses must be treated in all circumstances with the respect due to human dignity."²³⁰

Genetic studies outside the field of reproductive technologies have just begun. In a recent paper of the Medical Research Council of Canada committee on gene therapy, the use of genetic manipulation for enhancement purposes was considered as unlikely.²³¹ Furthermore, any techniques that would seek to improve such traits as intelligence are not scientifically feasible.²³²

The issue of genetic perfectionism involves weighing social obligations against individual rights and reproductive freedoms against notions of public order, public health and public welfare. Is there a right to a "healthy" genome? A brief review of wrongful birth and wrongful life suits and other related legal developments might provide some insights.

VI. Genetic Wrongs

In the last half-century, there has been an increase in knowledge of environmental teratogenic risks to the foetus and an increased ability to diagnose genetic conditions preconceptionally and prenatally. This laid the groundwork for suits following the birth of a child whose injuries were claimed to be caused by the fault of another. The fault could be direct harm to the foetus *in utero* causing it to be born injured. It could also be an incorrect diagnosis before or after conception followed by the birth of a child with malformations.²³³

In the first situation, the basis for recourse was the legal fiction that an unborn child can be considered born under law, provided this is in the child's interest. Thus, following the birth of a child who was alive and viable, parents could recover damages in the name of the injured child under the general principles of liability for negligence, even though the negligence occurred prior to birth.

230. *Recommendation 1046*, *supra*, note 97, s. 10; also see *supra*, notes 98-99. This was also the position taken in a Quebec governmental report on reproductive technologies entitled *Rapport du comité de travail sur les nouvelles technologies de reproduction humaine* (Québec: Ministère de la Santé et des Services sociaux, 1988) at 90 and that of the Barreau du Québec, "Rapport du comité sur les nouvelles technologies de reproduction" (1988) 48:2 suppl. R. du B. at 37-40.

231. See Medical Research Council of Canada, *supra*, note 30 at 12, which recommends restricting research to somatic cells as did other commissions around the world. See generally the Benda report, *supra*, note 39; Enquete Commission, *supra*, note 39; Commission d'experts, *supra*, note 38.

232. Friedrich Vogel and Arno G. Motulsky, eds, *Human Genetics: Problems and Approaches*, 2d ed. (Berlin: Springer-Verlag, 1986) (see especially Chapter 8, "Genetics and Human Behavior," at 584); Eve K. Nichols, *Human Gene Therapy* (Cambridge, Mass.: Harvard University Press, 1988) at 166.

233. Knoppers, *supra*, note 111.

In the second situation, that of faulty diagnosis or counselling, the suit of the parents for "wrongful birth" was based on the assumption that they would not have conceived or would have aborted the foetus legally in the absence of such fault. Subsequently, it was not long before claims for "wrongful life" were brought by a child on the child's own behalf. It was argued on behalf of the child that, had the parents been properly diagnosed or counselled, the child would not have been wrongfully conceived.

Parents' claims for wrongful birth have been granted in numerous cases under traditional legal principles of negligence. However, wrongful life claims by the child have met with resistance. Except in a few cases,²³⁴ the courts in all jurisdictions have denied what was perceived to be a request to measure life with a defect against no life at all. This, together with the problem of calculating damages for such a "wronged" existence, constituted insurmountable existential difficulties and an affront to the dignity and respect owed to all human life. In the exceptional cases where the claims were successful, the courts dismissed those arguments and side-stepped the legal problem of proving causation. Instead, they concentrated on the very real injury of the child, and on the fact that damages awarded to the parents only gave the child financial protection until the age of majority. Calculation of damages for the child was considered to be no more difficult than in other personal injury cases.²³⁵

Parallel to these developments in legal liability in respect of those not yet born has been the emergence of foetal protection policies. These have taken the form of restrictions or limitations to abortion, foeticide statutes to protect viable foetuses from criminal acts and the obtainment of court orders mandating certain behaviours by women during pregnancy or birth.²³⁶ In the next decade, we can expect embryonic life *in vitro* or in "storage" to be protected through the legislative regulation of reproductive technologies.²³⁷

Considering these legal developments, will the general obligation of individuals not to harm "others," together with the specific obligation of parents to act in the best interests of their child, form the basis of claims for birth defects that could have been

234. *Curlender v. Bio-Science Laboratories*, 165 Cal. Rptr. 477, 106 Cal. App. 3d 811 (1980); *Turpin v. Sortini*, 119 Cal. App. 3d 690, 174 Cal. Rptr. 128 (1981), rev'd., 182 Cal. Rptr. 337, 643 P. 2d 954, 31 Cal. 3d 220 (Sup. Ct 1982); *Harbeson v. Parke-Davis, Inc.*, 656 P. 2d 483, 98 Wash. 2d 460 (Sup. Ct 1983); *Procanik v. Cillo*, 478 A. 2d 755, 97 N.J. 339 (1984); *Siemieniec v. Lutheran General Hospital*, 480 N.E. 2d 1227 (Ill. App. 1 Dist. 1985). In the latter case, the wrongful claim was said to be derivative of the parents' wrongful birth claim.

235. For a recent Quebec case denying damages on the basis of the majority of American jurisprudence, see *Engstrom v. Courteau*, [1986] R.J.Q. 3048 (C.S.). See also Knoppers, *supra*, note 111, for the possible applicability of liability for injury to life *in utero*, *in vitro* or "in contemplation."

236. Rodgers, *supra*, note 112. See also Bonnie Steinbock, "The Logical Case for 'Wrongful Life'" (1986) 16:2 *Hast. Cent. Rep.* 15; Shaw, *supra*, note 110; Margery W. Shaw, "Should Child Abuse Laws Be Extended to Include Fetal Abuse?" in Aubrey Milunsky and George J. Annas, eds, *Genetics and the Law III* (New York: Plenum Press, 1985) 309; Bartha M. Knoppers, "Comparative Abortion Law: The Living Abortus" in K. Mason, ed., *Paediatric Medicine* (London: Chapman & Hall, 1989) 387-97; Knoppers, *supra*, note 89; *Crimes against the Foetus*, *supra*, note 113.

237. Knoppers, *supra*, notes 89 and 111.

avoided? If gene alteration were possible, this obligation could be seen as reasonable, in the same way that prenatal or post-natal therapy now is. Thus, according to one author, were parents to refuse gene alteration, the right to be born with a particular genome would be violated because that genome was available through gene therapy and would have prevented the severe handicap.²³⁸

The same author argues that procreative freedom:

must, at a minimum, include the freedom to prevent, either by abortion or by treatment before birth, the birth of a child with harmful genes. If it is permissible — indeed, even obligatory — to treat the child's condition after birth or prenatally, it should be permissible to treat the condition at the embryo or preconception stage as well, for it will save the offspring and their descendants the burden of doing it later. Indeed, the child might not otherwise be born, if the parents are limited to postnatal remedies. [Thus] the right to procreate includes a right to practice negative eugenics — to deselect harmful characteristics from future generations.²³⁹

One might agree that germ-line alteration is beneficial to future generations and avoids needless suffering. Or, one might accept that a person has the “right to prevent harm in one's offspring and their descendants.”²⁴⁰ But it is quite another argument to maintain that “offspring may have a right to gametic therapy from the parents when essential for a healthy genome.”²⁴¹

Considering the fact that gametic and germ-line alteration are still experimental, should potential parents be offered the choice of genetically “healthy” gametes or embryos from donors? Is there a duty to do so?

Unless reproductive choice includes the freedom to transmit “unhealthy,” “abnormal” or unaltered genes, the legal recognition of an obligation not to harm and to act in the best interests of descendants could mean that there is a duty to eliminate such genes and not just to treat the resulting disorder.²⁴² The right to an altered genome could mean that benefit would accrue to the individual (somatic alteration), or to future generations as well (germ-line therapy or recourse to donated gametes or embryos).

The outcome of this approach might be that potential parents would have a higher standard of duty to not-yet-conceived or not-yet-born children than they would have to their born and living children.

According to one author, “[p]rocreative freedom includes the freedom to avoid procreation and the freedom to procreate. The latter must include some measure of freedom to select or control the characteristics of offspring, such as to prevent harm to

238. John A. Robertson, “Genetic Alteration of Embryos: The Ethical Issues” in Milunsky and Annas, *supra*, note 236 at 115.

239. *Ibid.* at 125.

240. *Ibid.*

241. *Ibid.*

242. *Ibid.*

them.”²⁴³ This is not the equivalent of approved or enforced genetic choice as a condition for the right to reproduce. The notion of parental “rights” to healthy children would encourage physicians to suggest abortions or to select or eliminate unhealthy embryos for fear of legal actions. The advocacy of genetic “rights” of fetuses or born children would have similar consequences. While “[a] sizable number of people may argue that the right to have genetically diseased children, or even to transmit deleterious genes to future generations, must be limited or denied,”²⁴⁴ the resolution of such public problems must turn on “the willingness of society to bear the social costs of individual freedom.”²⁴⁵ It may seem anomalous (and even repugnant) that, in the name of religious or reproductive freedom, one deliberately and knowingly creates a child doomed to a life of suffering.²⁴⁶ Yet, in the rare cases where this option would be selected, is it not a necessary societal risk for the greater freedom of procreative choice? It would be equally repugnant to mandate procreative choices in the name of societal “normality.”

Respect for the inherent dignity of the human person 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. The legitimate rights of the injured child in cases of negligence by third parties cannot be extended to require parents to avoid giving birth to a genetically disabled child. The possibility of legal action by disabled children against their parents constitutes a grave threat to familial relationships. “In a society where individual values and mores are revered and closely guarded, legal actions by defective children against their mothers would seem to fly in the face of this reverence, and confound traditional freedom of choice.”²⁴⁷

We have seen that there are those who would compel parents to take certain reproductive decisions in order to avoid having children with serious medical disorders.²⁴⁸ However, parental choice could also be limited by limiting the availability of the technology and health care resources necessary to prevent such births. We saw that the Enquete Commission would ban, outright, manipulation of the genome (were such techniques feasible) because it considered such manipulation an affront to human dignity.²⁴⁹ A more important way that parental choice could be circumscribed is by

243. *Ibid.*

244. Kevles, *supra*, note 204 at 300.

245. *Ibid.*, Daniel Callahan as cited in Kevles.

246. Joseph Fletcher, *The Ethics of Genetic Control: Ending Reproductive Roulette* (New York: Anchor, 1974) at 187: “People who know a child will be defective, or could have known if they had cared but nonetheless allowed it to be born, are as guilty of wrongdoing as those who culpably contribute to a wrongful death.”

247. Catherine J. Damme, “Controlling Genetic Disease through Law” (1982) 15 U.C. Davis L. Rev. 801 at 837. See especially the convincing arguments in The Law Commission, *Report on Injuries to Unborn Children* (London: HMSO, 1974) at 23-26; Alexander M. Capron, “Tort Liability in Genetic Counseling” (1979) 79 Colum. L. Rev. 618.

248. See discussion of the hearings of the Council of Europe, *supra*, note 99ff. See also Kevles, *supra*, note 204, citing Paul Ramsey at 277; Shaw, *supra*, note 110; Fletcher, *supra*, note 246.

249. *Supra*, note 39 and following text.

limiting the availability of prenatal diagnosis. If our goal is to maximize reproductive decision making, we must find a way to have meaningful public discussion of policies that affect that freedom.

VII. Conclusion

The use of the language of rights in the genetic context favours conflicts and presumes that the present state of genetic ideologies (determinism, naturalism, discrimination and perfectionism) will continue. However, the future of human genetics does not lie in the obvious controversies surrounding manipulation or elimination. Rather it is in the elucidation and communication of genetic information, in genetic education and in informed genetic choices.

At present, the three areas of genetic testing (workplace, insurance and reproductive testing) pose risks of adverse genetic discrimination while at the same time providing information on cause and prevention. It is not too early to begin a societal debate on these issues with the aim of developing a coherent policy respectful of human rights and dignity. The development of such policy for social change should come from a process of public education so that it emerges from the participation of informed individuals. In other words, we should not wait to act until the effects of genetic discrimination and the promotion of genetic "naturalness" or "rights" are evident.

If we were to abandon the language of "rights to a particular genome," healthy or not, altered or not, what reasonable limitations, if any, could be envisioned in a free and democratic society, in accordance with section 1 of the *Canadian Charter of Rights and Freedoms*? What would be the ethical and legal framework that might maximize genetic information and freedom of choice, and yet limit potential abuses? What would constitute "genetic justice"?

CHAPTER SIX

Towards Genetic Justice

I. Introduction

The previous chapters have described the technical possibilities of the new human genetics and the complexity and variability of the individual and collective genetic heritage, and in them we maintain that the protection of our genetic heritage is essential for the preservation of human rights. In this chapter we will explore the normative and moral precepts underlying human rights legislation in the medical context. Do these principles require further elaboration or expansion because of the problems specific to human genetics? Is there a need for a new ethic for this scientific era? Now that we are moving from chance to control, that is, to the end of "reproductive roulette,"²⁵⁰ are we starting from a *tabula rasa*? Has the old alliance between humankind and creation been reduced "to a tenuous and fragile thread"?²⁵¹ If so, upon what values can we construct the foundations of our new responsibilities as we decipher the genetic language of "The Book of Man"?

This background of principles could serve as a standard of judgment or criticism, a "moral" well-spring,²⁵² against which to measure the applicability of current theories of justice derived from these principles, or we could search for new legal rules and systems — a new "genetic justice."²⁵³

While an ethical framework must form the basis for the construction of a theory of genetic justice, the formulation of a viable theory cannot be isolated from more pragmatic considerations. The social and economic costs of respecting or curtailing certain freedoms must be part of the discussion of public health policy. We must also take into account the clinical or research context, where ultimately the policies will be expressed. And most important, a theory of justice must consider the individual who will be affected by it, and who will thus influence its formation.

250. Fletcher, *supra*, note 246.

251. See Kurt Bayertz, quoting Jacques Monod in "Increasing Responsibility as Technological Destiny? Human Reproductive Technology and the Problem of Meta-Responsibility" in Durbin, *supra*, note 187, 135 at 146.

252. Alexander M. Capron, "Legal Rights and Moral Rights" in Hilton et al., *supra*, note 68 at 221-27.

253. This term was used by George J. Agich, in "Genetic Justice" (1986) 24 U.W.O. L. Rev. 39, who discussed the application of theories of justice to genetic engineering.

II. Ethical Considerations

The most comprehensive reviews of the ethical issues specific to genetic screening, counselling and therapy are found in the 1982²⁵⁴ and 1983²⁵⁵ reports of the American President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. More recently, other commissions dealing with reproductive technologies have begun to discuss the ethical and legal issues of those technologies in relation to human genetics. Notable among them are the Benda report from West Germany,²⁵⁶ the report of a group of experts of the Ministry of Justice in Switzerland²⁵⁷ and the Canadian report emanating from the Medical Research Council of Canada²⁵⁸ and the Science Council of Canada.²⁵⁹ Moreover, having been a forerunner in its recommendations to prohibit and control the more extreme applications of genetic engineering, the Council of Europe, through the work of its Ad Hoc Committee of Experts, is now studying genetic screening, counselling and therapy.²⁶⁰

Genetic testing, screening and counselling include: research, diagnosis, susceptibility testing, risk prediction, carrier testing, DNA banking, gene therapy, preconception counselling, prenatal diagnosis and the offering of reproductive choices including donor gametes or embryos. All of these raise ethical issues, some of which are new. Thus, we will examine some ethical principles common to medicine and human genetics: autonomy, beneficence and its companion, non-maleficence.

A. Autonomy

Autonomy, meaning self-rule, generally refers to a view that we have of ourselves and of others as being self-governing. Autonomy implies both physical and psychological control. The physical control has recently been held, in a California

254. *Splicing Life*, *supra*, note 33.

255. *Screening and Counseling*, *supra*, note 33. See also the excellent OTA reports on counselling and screening in human genetics, *Human Gene Therapy*, *supra*, note 26; *New Developments in Biotechnology*, *supra*, note 52.

256. *Supra*, note 39. See also Enquete Commission, *supra*, note 39.

257. Commission d'experts, *supra*, note 38.

258. *Supra*, note 30.

259. *Supra*, note 34.

260. Council of Europe, Ad Hoc Committee of Experts on Progress in the Biomedical Sciences (CAHBI), *Prenatal Genetic Screening, Prenatal Genetic Diagnosis and Associated Genetic Counselling* (Strasbourg: The Council, 1989).

case,²⁶¹ to include control over body cells and tissues. The cells of the plaintiff, John Moore, had been used in scientific research and for profitable commercial exploitation, because of the unique and valuable genetic information and properties they contained. The issue in the case was whether the plaintiff's physician could use the plaintiff's cells without his consent. The California Court of Appeal stated: "For better or worse, we have irretrievably entered an age that requires examination of our understanding of the legal rights and relationships in the human body and the human cell."²⁶² The Court held that "[a] patient must have the ultimate power to control what becomes of his or her tissues. To hold otherwise would open the door to a massive invasion of human privacy and dignity in the name of medical progress."²⁶³ Thus, respect for the person is often linked to autonomy. In the context of human genetics, the storage of DNA and the exchange of genetic information put in jeopardy this respect for the autonomous, independent actions of individuals.

Autonomy also includes the person's control over his or her choices and actions.²⁶⁴ In the previous chapter we saw how certain ideologies or beliefs can affect choice. For example, a person whose characteristics are considered predetermined by his or her genetic make-up is not considered as someone who has much choice. Persons with particular genotypes may then be barred from certain work environments because of their genetic make-up. There has been a gradual emergence of a quality-of-life ethic. This ethic is especially evident at the boundaries of conception and death. It is emerging in the questions surrounding the reproductive technologies, in the artificial measures used to sustain the dying and in the allocation of health care resources, to give but a few examples. If we view the quality of life of those destined to have inherited disorders as being so dismal that avoiding their birth is seen as the only option, parents lose their autonomy of reproductive choice.²⁶⁵

If, on the other hand, we view the availability of prenatal diagnosis as a move towards perfectionism, we may react by restricting the reproductive options parents have. Thus, there are many ways in which our ideologies or moral views may affect social and reproductive autonomy.

As early as 1972, it was recognized that genetic screening must be voluntary to preserve autonomy. The means to do so is through informed consent. The duty to inform is based on the moral principle of autonomy. Its goal is to protect against not

261. *Moore v. Regents of the University of California*, 249 Cal. Rptr. 494 (App. 2 Dist. 1988), reh'g granted 252 Cal. Rptr. 816 (1988). For a discussion of the plaintiff's claims under private law see Andrews, *supra*, note 8 and Marie-Angèle Hermitte, "L'affaire Moore" (December 1988) 417 *Le Monde Diplomatique* 20, 21.

262. *Moore v. Regents of the University of California*, *supra*, note 261 at 504.

263. *Ibid.* at 508.

264. John C. Fletcher, "Ethical and Social Aspects of Risk Predictions" (1984) 25 *Clin. Genet.* 25 at 25-26.

265. *Screening and Counseling*, *supra*, note 33 at 44; see also Robert M. Veatch, *The Foundation of Justice: Why the Retarded and the Rest of Us Have Claims to Equality* (New York: Oxford University Press, 1986).

only physical risk, which is minimal, but also "psychologic or social injury."²⁶⁶ One statement reads:

[W]e strongly urge that no screening program have policies that would in any way impose constraints on childbearing by individuals of any specific genetic constitution, or would stigmatize couples who, with full knowledge of the genetic risks, still desire children of their own. It is unjustifiable to promulgate standards for normalcy based on genetic constitution.²⁶⁷

Likewise, the President's Commission found no justification for compulsory screening, except to prevent serious harm to the defenceless (such as children). Even then, parental choices and freedoms were considered to be paramount.

The preceding pronouncements on the principle of autonomy were made before the widespread use of genetic testing *in utero*, before wrongful life suits by disabled children, before recourse to gamete or embryo donors for genetic reasons was possible and, certainly, before the possibility of experimental pre-implantation genetic testing or gene therapy.²⁶⁸ Those developments bring into focus that some harm is preventable, and thus, the principle of autonomy may come into conflict with the principle of beneficence.

Another area in medicine where autonomy has an important role is that of the maintenance of confidentiality, the guarding of shared secrets. In the context of genetic screening, it is a "principle [which] serves to protect the welfare of those screened and to guard against improper uses of information acquired through screening."²⁶⁹

The confidentiality issue will affect most people as population testing for susceptibility to common disorders becomes feasible.²⁷⁰ That is, genetic disease comprises not only rare single-gene disorders but also multifactorial disorders such as cancers, heart disease, diabetes, schizophrenia and so on, many of which are relatively

266. Special article, "Ethical and Social Issues in Screening for Genetic Disease" (1972) 286:21 N. Engl. J. Med. 1129 at 1131; see also National Academy of Science, *supra*, note 166.

267. Special article, *supra*, note 266 at 1130-31.

268. See, however, the warnings of the President's Commission, *Splicing Life*, *supra*, note 33 at 66:

If genetic engineering and related reproductive technologies enable a marked reduction of genetic defects and the burden they impose on their victims and on societal resources, however, mandatory genetic treatments may be advocated Future developments in gene surgery or gene therapy may lead to further departures from the principle that a competent adult may always refuse medical procedures in nonemergency situations and form the assumption that parenting and reproduction are largely private and autonomous activities.

And from *Screening and Counseling*, *supra*, note 33 at 55-56:

Such a response would be indefensible; the claims of a handicapped child on societal resources should not be dependent on the decision of the child's parents to undergo screening. Such a response would also be out of keeping with current efforts to assure rights and opportunities for the handicapped.

269. Fletcher, *supra*, note 264 at 27. See also *Screening and Counseling*, *supra*, note 33.

270. Dorothy C. Wertz and John C. Fletcher, eds, *Ethics and Human Genetics: A Cross-Cultural Perspective* (Berlin: Springer-Verlag, 1989).

common. This means that, soon, a large segment of the population could be subject to genetic surveillance, making problems of confidentiality more widespread.

The President's Commission said that genetic information should never be given to third parties such as employers or insurers without the explicit consent of the patient.²⁷¹ However, forbidding all third-party access may not be feasible. For example, the very nature of insurance requires that the insurer know of health risks, and employers may need such information to protect their workers. Thus, guidelines on confidentiality are needed to ensure respect for the dignity and autonomy of the human person and the person's right to employment or insurance.²⁷²

B. Beneficence

The second principle is that of beneficence, that is, serving the well-being of others either individually or collectively, by promoting their good. It implies balancing the benefits and harms of actions affecting others. For example, we saw that, in general, autonomy is achieved partially by maintaining confidentiality. However, this duty of confidentiality is not absolute and may be tempered when maintaining that confidentiality presents a potential for serious harm to others. The President's Commission held that confidentiality could be overridden in certain cases where blood relatives were at risk of serious harm.²⁷³ With the proliferation of genetic testing and the need to involve relatives in DNA linkage studies, we will need to re-examine the situations in which the revealing of genetic information to relatives at risk for serious harm will be justified.

C. Non-maleficence

Non-maleficence is the counterpart of the principle of beneficence.²⁷⁴ Its meaning, to do no harm, differs from beneficence in that in certain situations it may require a positive duty to achieve the goal of doing no harm. For example, we have seen that the principle of beneficence may, in some circumstances, require the autonomy of an individual to be reduced in order to prevent harm to others. However, the principle of non-maleficence might require more, namely, that the person with the confidential

271. *Screening and Counseling*, *supra*, note 33.

272. Employers should have to prove that exclusion of potential employees is related to and justified by an existing medical condition. Discrimination on the sole basis of susceptibility to common multifactorial disorders or to late-onset disorders should be prohibited. See above, Chapter Five.

273. *Screening and Counseling*, *supra*, note 33.

274. See generally H. Tristram Engelhardt, *The Foundations of Bioethics* (New York: Oxford University Press, 1986); Robert M. Veatch, *A Theory of Medical Ethics* (New York: Basic Books, 1981); Norman Fost, "Regulating Genetic Technology: Values in Conflict" in Milunsky and Annas, *supra*, note 236 at 15.

information have a positive duty to tell others. This can be likened to a duty to "rescue" so long as doing so does not involve danger or risk to oneself.²⁷⁵ Thus we may ask whether there is a positive duty to know one's genetic make-up and to reveal genetic information that is vital to a blood relative, in the making of the relative's life-style or procreative decisions; likewise it may be asked whether there is a positive duty to avoid conceiving a child who may be burdened with a known genetic disorder.

III. Theories of Justice

Principles of justice are founded not only on ethical principles but also on social concepts of fairness. Where resources are limited and there is competition, we must find a basis for allocating goods to individuals. Thus, there is the principle of distributive justice.²⁷⁶ Distributive justice requires that like cases be treated alike and different cases differently, in proportion to the relevant differences between them. Therefore, health care resources should be distributed on the basis of relevant differences between individuals.²⁷⁷ How do these ethical principles fit within the traditional theories of justice when we realize that everyone is genetically different, and that we share "genetic vulnerabilities"?²⁷⁸

A recent world-wide study of cross-cultural perspectives in ethics and human genetics identified the issue of fair distribution as being acute, especially at a time of increasing demand.²⁷⁹ What priority should genetic services have in a country's overall health care expenditures, particularly in those countries where prevention has become a major goal of medical care but resources are limited?

In the recommendations of a world-wide survey on the American health care system, the authors suggest that to attain fairness:

genetic services should be available to all persons equally, regardless of ability to pay, their geographical location, views about abortion, education or ethnic origins. Persons who pay for special services should not be given priority. Commercial labs should be reimbursed by the government and should be regulated so that they serve all persons

275. An affirmative obligation to rescue is unique to the civil law. See, e.g., *The French Penal Code*, G.O.W. Mueller, ed. (South Hackensack: Fred B. Rothman & Co., 1960) art. 63, and the Quebec Charter, *supra*, note 76, s. 2. For a study of the common law approaches, see Law Reform Commission of Canada, *Omissions, Negligence and Endangering*, Working Paper 46 (Ottawa: The Commission, 1985) at 17.

276. The common definition of distributive justice is entitlement based on needs. See *infra*, note 287.

277. Rebecca Dresser, "Social Justice in New Reproductive Techniques" in Milunsky and Annas, *supra*, note 236 at 159-60.

278. Nolan and Swenson, *supra*, note 168 at 42. See also Schirmacher in Durbin, *supra*, note 187 at 211: "[W]e must still learn to use the variability of our existence."

279. Wertz and Fletcher, *supra*, note 270.

equally and so that they perform only medically indicated procedures under the guidelines set for government or university settings.²⁸⁰

Application of this principle would require governmental regulation and surveillance of genetic services beyond the public health sector to the private and commercial.

Traditional theories of justice that attempt to find a basis for distribution of resources can be classified as utilitarian, libertarian or egalitarian.²⁸¹ In the context of health care, and all the more so in a system of socialized medicine, a fourth classification can be added: that of John Rawls' social contract.²⁸²

A. Utilitarianism

Utilitarians measure justice in terms of the greatest overall good. "In this framework, unequal treatment of individuals is morally permissible if the aggregate harm that such [unequal] treatment produces is less than the aggregate benefit that it produces."²⁸³ However, there are problems in the application of this theory. First, leaving aside the problem of measuring benefit and harm in the health care context (beneficence), utilitarianism reduces all human goods or choices to a single scale rather than recognizing the diversity of human behaviours and choices. We know, however, that life and health are not "commodity values."²⁸⁴ Second, this cost-benefit approach embodies a high standard of rationality. We know, however, that workplace or career choices are often seen by others as "irrational,"²⁸⁵ as may be the choices of individuals

280. Personal communication of John C. Fletcher and Dorothy C. Wertz, to the Science Council of Canada, Committee for the Study of Genetic Predisposition to Disease, 1988.

281. See Joel Feinberg and Hyman Gross, eds, *Philosophy of Law*, 3d ed. (Belmont, Calif.: Wadsworth Pub., 1986).

282. John Rawls, *A Theory of Justice* (Cambridge, Mass.: Belknap Press of Harvard University Press, 1971).

283. Dresser, *supra*, note 277 at 161.

284. Elizabeth Anderson, "Values, Risks, and Market Norms" (1988) 17 Phil. Pub. Aff. 54. See also Angus Clarke, "Genetics, Ethics, and Audit" (1990) 335:8698 *Lancet* 1145 at 1147, 1146, who warns against "the simplistic application of cost-benefit analysis to the population provision of genetics services. In particular, such analysis should not be used as an audit of the effectiveness of genetics units." To do so puts "pressure upon clinicians to maximise the role of terminations of pregnancy for 'costly' disorders."

285. Anderson, *supra*, note 284 at 59.

What is needed is an interpretive method which attempts to understand human action in the terms the agents use to understand themselves. In order to evaluate the relevance of the data used by cost-benefit analysis, we thus need to find out how people understand their market choices about risks to life and health.

or couples following genetic counselling.²⁸⁶ Thus, the utilitarian approach in human genetics would undermine freedom of choice (autonomy) and consequently, respect for human dignity.

B. Libertarianism

The principle of autonomy is of major importance to libertarians. Libertarian theories of justice are grounded in the philosophy of John Locke. They hold paramount the free disposition of one's property and of one's body. A libertarian approach to policy making presumes both a minimum of government interference and informed and free decision making on the part of individuals.²⁸⁷ "This freedom overrides any conflicting societal interest in providing equal access to health care. For libertarians, the free market and its attendant inequities reign in a just health-care system."²⁸⁸

In the context of human genetics, the libertarian view prizes the inequality of the genetic distribution. Thus one's genes, considered under this view to be private property, would be subject to free market forces "in which one's genetically-determined strengths and weaknesses can develop."²⁸⁹ This form of social Darwinism is incompatible with the universality of the Canadian health care system which is based on an egalitarian principle.

C. Egalitarianism

Egalitarian justice emphasizes respect for persons as being equal by the very fact of their being human. Drawing from the Rousseauian tradition, all human beings are considered to be of equal moral worth with an equal right to well-being and freedom.

286. According to Emery et al., as cited in Sherman Elias and George J. Annas, *Reproductive Genetics and the Law* (New York: Yearbook Medical Publications, 1987) at 51, "a third of those who were told they were at high risk of having a child with a serious genetic disease were undeterred and actually planned further pregnancies." For an analysis of how parents do make reproductive decisions, see A. Lippman-Hand and F. Clarke Fraser, "Genetic Counseling — The Postcounseling Period: II. Making Reproductive Choices" (1979) 4 Am. J. Med. Genet. 73.

287. For a libertarian view of justice in health care see Engelhardt, *supra*, note 274 at 85. For a criticism of Engelhardt's approach, see Robert M. Veatch, Book Review of *The Foundations of Bioethics* (1986) 105:6 Ann. Intern. Med. 987 at 988:

Engelhardt's concept of justice in health care is one based merely on freely made deals in which people with power get whatever they can get. Those who have lost in the natural or social lotteries, who are medically needy because of genetic or social deprivation, are just out of luck unless aided by charity.

See also Engelhardt's and Rie's refutation of the ethic of distributive justice in H. Tristram Engelhardt and Michael A. Rie, "Morality for the Medical — Industrial Complex" (1988) 319:16 N. Engl. J. Med. 1086. For a further criticism of Engelhardt, see Veatch, *supra*, note 265.

288. Dresser, *supra*, note 277 at 161; *New Developments in Biotechnology*, *supra*, note 52.

289. Agich, *supra*, note 253 at 43.

The egalitarian view regards "the inequality of the natural distribution as a moral predicament requiring remedial social action [and] presupposes that each individual has an equal claim on the totality of assets and liabilities which comprise the gene pool."²⁹⁰ The goal of egalitarianism is to modify social institutions so as to minimize or compensate for unequal opportunity.

The problem with the egalitarian approach is that it may conflict with liberty. As we have seen,²⁹¹ liberty or free choice is an important element in protecting the inherent dignity of the person, which is the underlying basis of international and Canadian constitutional law. Most would agree that at least minimal distributive justice is required to compensate for the disparities within a society.²⁹² However, "[s]ome would probably go beyond this and contend that substantial equality is a necessary condition of respect for the intrinsic worth of the human person."²⁹³ Therein lies the conflict because "such egalitarian objectives cannot be realized without excessive curtailment of individual liberty and the use of coercion."²⁹⁴ Thus, a new theory of justice is required.

D. Social Contract

John Rawls, in his *A Theory of Justice*,²⁹⁵ describes the distribution of natural endowments as neither just nor unjust, but simply a fact. Rather, it is the way that institutions deal with this fact that gives rise to justice or injustice. His social contract theory of justice is based on what a society of rational individuals would decide to be just if they did not know what their actual lot in life would be with regard to natural talent or social status. Thus, Rawls assumes that the future is hidden by a "veil of ignorance" and from this "original position" participants in the social contract will devise a self-interested system of justice. The result would be, firstly and necessarily, that each person would have the most extensive liberty compatible with a similar liberty for others. Secondly, there would be equality of opportunity. Thirdly, any inequality resulting from differences in natural ability or merit would be adjusted in a way that would give the greatest benefit to the least advantaged. This is called the "difference principle." How, then, can this social contract approach be applied to human genetics?

The President's Commission²⁹⁶ considered Rawls' theory of justice in the context of health care. It foresaw that one could substitute the notion of one's initial genetic

290. *Ibid.*

291. Above, Chapters Two and Four.

292. Schachter, *supra*, note 116 at 851.

293. *Ibid.*

294. *Ibid.*

295. Rawls, *supra*, note 282.

296. *Splicing Life*, *supra*, note 33 at 68. See also *New Developments in Biotechnology*, *supra*, note 52.

assets for the lottery of social or natural assets described in Rawls' social contract theory. Thus, inequalities of opportunity arising from one's genetic constitution could be minimized through intervention in this natural biological lottery. The values of liberty and equality could be realized through the participation of "reasonable" citizens²⁹⁷ who would devise a system of co-operation to their mutual advantage.²⁹⁸

Rawls' theory of justice has been applied by George Agich to develop a theory of genetic justice.²⁹⁹ In Rawls theory, genetic inequalities would be dealt with by a readjustment of inequalities in a way that would work for the good of the genetically less fortunate. Agich argues that genetic attributes should be included in the original position, because knowledge of the possibilities for genetic intervention is necessary to decide what is just.³⁰⁰ He also argues that decisions as to whether to prevent or to treat genetic disease would require some alterations of Rawls' theory, to allow those in the "original position" to deal with future generations. Furthermore, as he points out, no disease is purely genetic and therefore what is required is knowledge not only of genetics but also of environment and of the possibilities for social remedial action. Thus, "[t]he predictive uncertainty and potential long-range consequences of human genetic intervention when coupled with the possibly reductive character of genetic explanation have important implications for the task of justifying the practice of genetic screening and treatment especially in terms of the principle of justice."³⁰¹

We agree with Agich that Rawls' theory needs to be altered so that those in the original position (veil of ignorance) are given genetic information. However, this should be done in a way that not only promotes the individual, but also ensures informed participation in the new social contract. Such participation would come from the enlightened notion that "the collective human gene pool knows no national boundaries but is the biological heritage of the entire human species."³⁰² Thus, the social contract could be reconsidered on the principle of informed genetic equality.

297. John Rawls, "Justice as Fairness: Political Not Metaphysical" (1985) 14 Phil. Pub. Aff. 219. In this article at 237, note 20, Rawls explains that it was an error in his seminal work, *supra*, note 282, "to describe a theory of justice as part of the theory of rational choice."

298. *Ibid.* For an excellent critique of Rawls, see Catherine Audard et al., eds, *Individu et justice sociale: autour de John Rawls* (Paris: Seuil, 1988). See also Marie-Angèle Hermitte, "Le droit civil du contrat d'expérimentation" in Fondation Marangopoulos pour les Droits de l'Homme, *supra*, note 194, 38 at 39:

Les tendances actuelles de l'expérimentation sur l'homme répondent donc assez exactement à la philosophie de John Rawls, mélange d'utilitarisme et de respect des droits de l'homme; l'utilitarisme fournit la base de raisonnements que la philosophie des droits de l'homme et du contrat social vient réorganiser plus ou moins profondément.

299. *Supra*, note 253.

300. *Ibid.* at 47.

301. *Ibid.* at 42.

302. Clifford Grobstein and Michael Flower, "Gene Therapy: Proceed with Caution" (1984) 14:2 Hast. Cent. Rep. 13 at 16.

Furthermore, we need not consider that our genetic lottery is something that makes us unequal. We now know that every individual is genetically unique.³⁰³ Individual difference could be interpreted as the underlying basis of the principle of equality.³⁰⁴

IV. New Ethical Principles

If knowledge of genetic differentiation will permit the development of the social contract from a position of informed "genetic equality" as we have suggested, what additional ethical principles should contribute to a formulation of the social contract? Two founding principles are suggested, the first being that of reciprocity³⁰⁵ — of exchange, and the second being that of mutuality — of civic responsibility. The two could constitute the ethical principles of checks and balances emanating from an informed citizenry, rather than from ignorance or state prerogative.

A. Reciprocity

The first founding principle of the new social contract is reciprocity, or exchange. It recognizes a "difference," that is, an inequality between the knowledge held by ordinary individuals and that held by practitioners of medical genetics. Justice requires that such knowledge be redistributed in a way that is beneficial to the less well-informed, that is, the ordinary citizen. A redistribution is essential to ensure that knowledge of medical genetics is not used by the state to impose decisions on individuals and to monitor their compliance. To ensure that it is the least advantaged who benefit from this exchange of knowledge, the exchange is best conducted within the physician-patient relationship, which has traditionally provided protection for the patient.³⁰⁶ This protection comes in the form of the doctrine of informed consent, based on the principle of autonomy. Traditionally, informed consent implied the communication of risks of physical harm. Today, it includes the avoidance of psychological and social prejudice, not only to the participant, but also to the participant's family and to society at large. Through informed consent, individuals are given the power to act on risk information in a way that is best for them, and even to decide whether they want to know of certain risks.

303. See above, Chapter Four, note 140.

304. Bartha M. Knoppers, "Human Genetics, Predisposition and the New Social Contract" in International Conference on Bioethics, *supra*, note 29 at 168.

305. Rawls, *supra*, note 282, uses this term to mean co-operation which is not the same as our interpretation of reciprocity as meaning exchange or transfer. Co-operation, however, is the traditional meaning of the term reciprocity: see Feinberg and Gross, *supra*, note 281 at 416.

306. Knoppers and Laberge, *supra*, note 91 at 1024.

Such individual control and

[t]he protection of free choice depends on an educated citizenry aware of the purposes of genetic tests as well as of their benefits, costs, and risks. This can be approached in a general way by improving public education but, more specifically, by assuring that genetic tests are only performed when the person offered the test has substantial understanding and will not be penalized as a result of either choice being made. That is informed consent.³⁰⁷

A truly informed consent also implies an educated and informed medical body; this is an urgent priority.³⁰⁸ It requires a transfer of knowledge from the molecular biologist or geneticist to the general practitioner. If the aim is true reciprocity in the patient-physician relationship, the greater goal of mutuality, of community, of civic responsibility can be achieved.

B. Mutuality

The second founding principle of the new social contract is mutuality or civic responsibility. It recognizes that genetic diseases affect not only individuals but also families and communities. Recognition of that fact gives rise to a need for a responsible sharing of genetic information. Thus, mutuality is based on the principle of beneficence and is compatible with the principle of liberty or free choice which "implies proper regard for the responsibility of individuals."³⁰⁹

Under the principle of mutuality, the individual is supplied with genetic knowledge and is at liberty to act upon it. However, individuals who do not act remain bound by the classical social contract. Under that contract, the individual continues to submit to state-imposed exceptions to individual freedom based on the notion of the "common good." The "common good" might be perceived by the state as including imposed eugenic programs. Thus, the maintenance and survival of individual liberty actually reside in civic participation.

At the family level, the individual would have a social obligation not to withhold information useful to other members of the family, where to do so could cause harm. Thus, mutuality is based on the principle of non-maleficence. In the exception, where after counselling a patient still refuses to inform relatives who are consequently subject

307. Holtzman, *supra*, note 40 at 629. See also David Roy and Maurice de Wachter, *The Life Technologies and Public Policy* (Montreal: Institute for Research on Public Policy, 1986) at 148-49.

308. Holtzman, *supra*, note 40 at 626-28. Without this reciprocity and open, truthful exchange as to what DNA sampling and the search for markers and the gene entail, we risk the development of legal protectionist policies based on notions of property, ownership, copyright and patent law instead of viewing the genetic information as an attribute of the person.

309. Schachter, *supra*, note 116 at 850.

to serious genetic risk, information relevant to family planning or to one's life-style could be communicated by the physician in spite of such a refusal.³¹⁰

At the community level, the individual could freely participate in DNA sampling, banking and the use of markers aimed at establishing linkage maps.³¹¹ This participation is the first step in the planning of preventive health care programs. Such programs should respect individual genetic differences and freedom of choice in decision making.

In return for patient participation and communication, the state would have the mandate to provide the resources not only for diagnosis but also for education in research, treatment and care. Education must be broad in scope. The goal of mutuality is to come to an understanding that will allow us to protect what is human in our genetic nature and yet allow us the freedom to relieve suffering and to progress as a species.

Thus, we must explore what human dignity means in the context of human genetics. We must beware of the tendency "to consider against human dignity whatever one intensely, if irrationally, dislikes. This way, through the breach of human dignity, one can smuggle into positive law personal ideologies in the form of norms binding the legislature."³¹²

It would be ironic if respect for the inherent dignity of the human person became the source of self-directed genetic imperialism. This imperialism could take the form of a program seeking to wipe out "bad" genes in the name of the genetic rights of future generations, or a prohibition against all genetic therapies affecting the heritage.

The debate must not remain polarized. A polarized debate makes use of "bad axioms" that have the "power to convince the hearer that a partial insight comprises the whole truth."³¹³ One such axiom is that of the slippery slope. The fear of "slipping" as a reason to halt genetic engineering is equivalent to denying afflicted individuals therapies "on the ground that we cannot make distinctions between remedial germline alterations and eugenic enhancements [and] indicates a lack of trust in the human ability to act discriminately on the basis of distinctive ethical classifications."³¹⁴

310. This position is consistent with that of the President's Commission, *Screening and Counseling*, *supra*, note 33 at 44. The author takes "family" to mean one's social and personal relationships, not only those legally recognized.

311. See above, Chapter One, under the heading, "V. The Changing Practice of Medical Genetics."

312. Jan Stepan, "State Intervention in Family Procreation Decisions" (1988) Reports II (VIIIth World Congress on Medical Law) [unpublished] 233 at 237.

313. Boone, *supra*, note 2 at 10.

314. *Ibid.* at 11. See also Fletcher, *supra*, note 246 at 5ff, on the errors of the capacity fallacy (we can do something, so we ought to) and the necessity fallacy (we can do something, so we will).

V. Conclusion

The utilitarian moral principle underlying the public health model, with its cost-benefit calculation, is an inappropriate model considering the problems of privacy and free choice posed by new genetics.³¹⁵ The social contract theory of justice offers more promise in giving meaning to the inherent dignity of the human person in the field of human genetics.³¹⁶ We propose that a new social contract be developed from a position of informed genetic equality. Such a contract would be based on the principles of reciprocity and mutuality.

Reciprocity, or exchange of knowledge, would occur within the traditional protected relationship of the physician and patient. In this way, individuality, confidentiality and freedom of choice could be preserved.

Genetic disease implicates not only the individual but also the family, the community and future generations. This fact imposes a duty on the individual to contribute to the detection and understanding of genetic disease and illustrates a need for the principle of mutuality or civic responsibility. This responsibility could be met by voluntary participation in such programs as the banking of DNA. In exchange, the state would provide resources in the areas of research, education, diagnosis, treatment and care.

The two principles, namely, of reciprocity and mutuality, would constitute a solid basis for shared responsibility and for patient participation in the practice of genetic medicine, with a view to establishing genetic justice based on individual genetic responsibility.

315. Ruth Macklin, "Mapping the Human Genome" in Milunsky and Annas, *supra*, note 236 at 107-11.

316. Hermitte, *supra*, note 298 at 43:

Il faut suivre pas à pas la théorie générale des obligations; elle est probablement plus liée qu'on ne l'imagine généralement à la protection des droits de l'homme, ou du moins à un type de protection, empirique certes, mais relativement proche, finalement, du message des droits de l'homme.

Conclusion

We have seen that human genetics offers the promise of the capacity to predict many diseases, both rare and common. Soon, most of the world's population may be touched by this capacity, either directly or indirectly. In the past, many couples did not know that they were carriers for a disease-causing recessive gene until they had a child with the disorder. In the future, many individuals will discover that they are carrying alleles for disorders of which they have no personal understanding. Previously, for late-onset diseases, a person known to be at, say, a 50 per cent risk from his or her family history would live with uncertainty as to whether he or she had the gene and would develop the disease. Now, such an individual may have more information on which to base choices. For common multifactorial diseases, particular gene markers can now warn persons that they have a higher probability than the rest of the population of developing a particular disease.

Eventually, we will have the technical ability to "treat" the gene itself. This will be possible in somatic cells for some single-gene disorders, but is likely to remain impractical in germ cells, even if technically feasible. For now, a wide gap exists between our ability to identify particular genes and our ability to treat them. Thus, a couple in which both partners carry a gene for a recessive disorder may have to decide whether to risk having children, or whether to avoid the risk by using prenatal diagnosis and selective abortion or by using reproductive technologies. These decisions will be influenced by, and will be likely to influence, our views of the disabled. Individuals at risk to inherit disease-causing genes may be under social and medical pressure to know whether they have the gene, and if so, to tell family members whose lives may be affected by that knowledge. Likewise, employers and insurers may have a stake in having such information. Individuals at risk for multifactorial disorders may be under close scrutiny to do what they can to avoid developing a disease by manipulating their environment or life-style. All of these changes will affect our daily lives as individuals and our future as a society.

The Council of Europe recommended in 1982 that there be a right to an unaltered genetic heritage based on the notion of human dignity. Thus, we examined the notions of genetic heritage and human dignity.

We saw that, through the biological processes of mutation and meiosis, each of us is unique and yet genetically tied to one another in both time and space through the collective gene pool. We saw that gene therapy of the somatic cells would have a small, indirect effect on the gene pool, as does conventional medical treatment, and that germ-line therapy, if it were possible and practical, would have a small direct effect. However, there is a moral difference between the two, because somatic therapy affects a single genome and may be seen as a private matter whereas gene therapy, by

directly affecting our gene pool, may be seen as a public matter. This conjures up the murky political history of the eugenics movement. This history is relevant not only to germ-line manipulation, which seems unlikely to occur, but also to the manipulation of individuals by more conventional social means such as discrimination.

Although the human person is more complex than a set of genes, our genetic make-up is perceived as an important part of the human person and thus an important constituent of human dignity. The meaning of human dignity has not been fully interpreted in international law, but that human dignity is its underlying theme, and all human rights are seen as deriving from it. The same can be said of the *Canadian Charter of Rights and Freedoms*, although it does not explicitly use the term, human dignity. Important components of dignity, autonomy and equality can be seen in the various sections of the *Charter*. We mentioned that these guarantees may have direct applicability to genetics in a number of ways relating to genetic testing and the use of DNA samples.

How our genetic heritage is to be protected is not clear. There is international consensus on the need to prohibit the more extreme possibilities of human genetics. However, we must learn to exercise caution without placing an *a priori* prohibition on all research affecting the gene. As with any technology, we must ensure that it does indeed lead to more choice, not less. Not only do we need to regulate with respect to abuse, we should also question the direction of the inquiry into genetic knowledge. We must decide on the limits of free choice to maintain that direction, and we will have to find a formula that respects the complexity, variability and uniqueness of the human person.

We reviewed the danger of creating a right to an unaltered genetic heritage, as proposed in 1982 by the Council of Europe. Under the guise of protection, such an interpretation could lead to genetic pre-selection, to genetic screening for suitability and, ultimately, to lawsuits within the family and between generations. Human beings are complex; our genetic uniqueness is only one factor making up our humanness. We have the ability to interact with, and to re-create, our environment. The laws and social policies we devise may be influenced by a view of the human person that is less than this view. Genetic determinism holds that we are fixed by our genes and thus we cannot create a social environment that accommodates biological differences. This position could have important consequences. It may lead to policies that manipulate the person out of certain environments (for example, the workplace) rather than manipulating the environment and social structure to fit the person. This view might also be evident in prenatal diagnosis. To eliminate fetuses with biological imperfections may seem simpler and less costly than to devise a social and educational system that accommodates them as children. In its extreme form, genetic determinism has led to suggestions that children who would inherit certain genetic disorders have a right not to be born, and consequently, potential parents have the duty to see that they are not.

An equally reductionist view of human nature is that of the "naturalists." According to genetic naturalism, the random diversity of our genetic constitution is seen as the essence of our humanity. Thus, any attempts to change it would be an

affront to human dignity. Such a stance precludes a discussion of when genetic alteration might be morally acceptable and reduces our scope for progress as a species. Under this view, any prevention of human suffering through genetic therapy could be considered an affront to our humanness, because chance biological diversity is an important part of it. Therefore, those who hold the naturalist position might restrict funding for genetic technology and medical services.

How can we reconcile these polarized views so that our uniqueness can serve as a source of respect for the individual and for collective humanity? What kind of legal and ethical framework can we devise to maintain free choice while limiting abuse and undesirable social side-effects?

Such questions led us to explore a theory of genetic justice to achieve those ends. We saw that the ethical principle of autonomy may conflict with the principles of beneficence and non-maleficence, which thus do not provide us with an answer. Principles of justice or fairness are broader and consider how resources can be fairly allocated. Utilitarian theories of justice present serious problems because the individual becomes the means to achieve a goal of efficiency, usually economic efficiency. The disabled may come to be seen as an "avoidable cost."

A libertarian theory of justice for health care takes the form of social Darwinism, and egalitarianism may conflict with our view of liberty or free choice which, like equality, is an important element in the protection of our inherent human dignity.

A theory of justice based on social contract could allow for both the protection of individual rights and the promotion of community responsibility in genetics. It depends on a societal commitment to the dissemination of knowledge of human genetics with its language of probabilities, probes and prediction. To so inform the population requires public education at all levels, the medical contract remaining as the privileged and confidential focus of the individualization of that knowledge. The principle of respect for autonomy resides in the informed consent of the individual and in voluntarism within a society that provides the foundation of public knowledge and understanding of genetic difference and genetic vulnerability.

The necessary international debate must recognize that the genetic pool has no political, social or racial boundaries. The meaning and the protection of the inherent dignity of the human person also includes the dignity of mankind and must necessarily be international in scope.

The new human genetics requires that a more thorough examination be made of the human rights questions it raises. We have only alluded to the issues of discrimination, insurance, employment, the rules of evidence, data-sharing or theft and especially the possible impact of the new human genetics on health policy and legislation. More study is needed into the particular ways that it will affect the social fabric of Canadian society, in particular with regard to the adequacy of current public and private law concepts. The impact of the new human genetics on the common law

and on the Quebec civil law of contracts, property, intellectual property, family law, the law of persons and liability needs to be examined.

The protection of human rights within a genetic context will have a high economic cost, not only for the technology but, more importantly, for education and the provision of genetic services. We will have to decide how much of our social resources we are willing to spend on this and how genetics will rate in relation to other equally expensive procedures.

Individuals as moral agents are responsible for genetic choices, for controlling their genetic "capital" or investment. Such choices must be informed and must consider societal implications and context. The multiplication of technological possibilities is not equivalent to a technological imperative. Rather, it demands responsibility on a societal level. We return in this way to the notion of genetic heritage as being individual and also the common heritage of humankind, a heritage held in common trust.

Glossary

ALLELE. One of two or more alternative forms of a gene at a specific site on a chromosome.

AMNIOCENTESIS. A medical test in which a needle is used to withdraw a small amount of amniotic fluid surrounding the foetus in the uterus. This fluid contains foetal cells. These are grown in cell culture and analyzed for a variety of chromosomal or biochemical disorders.

AUTONOMY. In ethics, the principle that independent actions and choices of an individual should not be constrained by others.

AUTOSOME. Any chromosome other than the sex chromosomes.

BENEFICENCE. Mercy, kindness or charity. In ethics, it is the principle that one has a duty to confer benefits or to help others further their legitimate interests.

CARRIER. An individual who has one disease-causing allele rather than the two necessary for the expression of a recessive disorder, or someone who has a dominant disease-causing gene that has not yet resulted in overt disease.

CELL. The fundamental unit of the structure of living organisms. The smallest membrane-bound protoplasmic body, consisting of a nucleus and its surrounding cytoplasm, capable of independent replication.

CHROMOSOME. The thread-like structure within the nucleus of a cell, containing DNA, the hereditary material (*i.e.*, genes). The normal number of chromosomes in humans is 46 — 22 pairs of autosomes and two sex chromosomes (XX or XY).

CHROMOSOMAL DISORDERS. Disorders resulting from additions or deletions of entire chromosomes or parts of them.

CLONING. The process of producing a group of cells (clones), all genetically identical to the original ancestral cell. In DNA technology, it is the process of producing multiple copies of a single gene or segment of DNA.

CROSSING OVER. The exchange, during meiosis, of chromosomal material between the paired chromosomes, one of which derives from the mother and one from the father. This process allows for greater variability than if chromosomes were inherited *en bloc*.

CYSTIC FIBROSIS. An autosomal recessive disorder with a high frequency in whites. The major clinical problems are caused by obstruction in the ducts of organs by abnormally thick secretions. The chromosomal location of the gene for this disorder is now known.

DETERMINISM. The theory that, for every human action, there are causal mechanisms such that no other action is possible.

DNA, DEOXYRIBONUCLEIC ACID. A double-stranded molecule, held together by weak bonds between base pairs of nucleotides, that encodes genetic information. There are four nucleotides in DNA: adenosine (A), guanosine (G), cytidine (C) and thymidine (T). Base pairs form only between A and T and between G and C, thus the sequence of each single strand can be deduced from that of its partner. This complementarity is the key to the information-transmitting capabilities of DNA. The information coded by DNA of the gene determines the structure, and thereby the function, of the corresponding protein.

DNA FINGERPRINTING. Laboratory analysis of a person's DNA — so called because, like fingerprints, a person's DNA is unique.

DNA PROBE. See GENE PROBE.

DNA SEQUENCE. The order of base pairs whether in a length of DNA, a gene, or a chromosome.

DOMINANT. Each somatic (body) cell has two copies (alleles) of the gene at any specific locus. An allele that is expressed regardless of the nature of its companion allele is said to be dominant (compare with recessive).

DOUBLE HELIX. The form in which two helical strands of DNA are bound together, looking much like a twisted rope ladder.

DOWN SYNDROME. A chromosomal disorder caused by the presence of an extra 21st chromosome (trisomy 21). The signs are mental disorder, congenital heart defect, a typical facial appearance and a reduced life expectancy. Down syndrome shows an increase in frequency with advancing maternal age.

EUGENICS. Attempts to improve the hereditary qualities of a population by encouraging transmission of traits judged to be desirable (positive eugenics) and discouraging those judged to be undesirable (negative eugenics).

EXPRESSION. See GENE EXPRESSION.

EXPRESSIVITY. The variability with which a given gene is expressed, by outward signs, in different individuals bearing the gene.

GAMETE. A sperm or egg. The mature male or female reproductive cell, which contains one set of chromosomes rather than the two sets found in somatic cells.

GENE. The fundamental physical and functional unit of heredity. A gene is an ordered sequence of nucleotides that make up the DNA located in a particular position on a particular chromosome.

GENE EXPRESSION. The process by which a gene's DNA sequence is converted into the trait that it controls.

GENE MAP. See **LINKAGE MAP.**

GENE POOL. All of the alleles of all of the individuals in a population.

GENE PROBE. A segment of single-stranded DNA that is labelled with a radioactive or other chemical marker and is used to identify a specific region of the genome.

GENE THERAPY. Insertion of normal DNA directly into cells to correct a genetic defect.

GENETIC MARKER. A readily recognizable genetic difference that occurs frequently enough to be useful in family and population studies.

GENOME. The total genetic material contained in the chromosomes of an individual's cells.

GENOTYPE. The genetic constitution of an individual with respect to a particular gene locus or the entire complement of genes, as contrasted to the outward appearance, the phenotype.

GERM LINE. The cell line that produces gametes (sperm or egg) for reproduction. Any changes to the germ line may be passed on to the next generation.

HAEMOPHILIA. A group of hereditary disorders that causes a condition in which it takes an abnormally long time for blood to coagulate. Classical haemophilia is X-linked. This means that it usually occurs in males and is transmitted to offspring by asymptomatic females, or by an affected male to all of his daughters.

HUNTINGTON'S DISEASE — HUNTINGTON'S CHOREA. A dominantly inherited disease usually manifest between the ages of 30 and 50. It results in slowly progressive degeneration of specific brain tissues and, ultimately, in death. The primary signs are disorders of movement (chorea) and dementia. The chromosome on which the gene is located is now known.

IN VITRO. Manipulations done on biological systems outside the intact organism.

JUSTICE. Generally refers to fair and equal treatment. In ethics, it is the principle that one should act in such a manner that no one bears a disproportionate share of benefits or burdens.

LINKAGE. The tendency of genes at different loci to be inherited together. The closer the loci are on a chromosome, the greater the linkage. The further apart they are, the more likely it is that they will be inherited independently as a result of crossing over during meiosis.

LINKAGE MAP. A map of the chromosomes showing the relative positions of particular genes.

LOCUS. The particular location of a gene on a chromosome.

MARKER. See GENETIC MARKER.

MEIOSIS. Cell division that occurs only in the germ cells during the formation of the egg and sperm. During this process, the number of chromosomes is reduced by half.

MENDELIAN TRAIT OR DISORDER. A trait or disorder that is controlled by a single gene, and that shows a simple pattern of inheritance (dominant or recessive, autosomal or X-linked). It is so named because traits of this sort were first recognized in peas by Gregor Mendel, the Austrian monk whose research laid the basis for modern genetics.

MRNA, MESSENGER RIBONUCLEIC ACID. A molecule that is complementary to the DNA of a specific gene and that moves from the nucleus to the cytoplasm where it serves as a template for the assembly of amino acids into proteins, which are the building blocks and enzymes of cells.

MULTIFACTORIAL. Traits or disorders whose expression results from several genes and environmental factors acting in concert.

MUTATION. A change in the genetic material that results in a new characteristic. When mutation occurs in a germ cell, it can be passed on to subsequent generations.

NATURALISM. The view that an essential element of human beings is that we are a product of chance.

NON-MALEFICENCE. Generally associated with the maxim *primum non nocere*, meaning, above all, do no harm. In ethics, it is the principle that one has a duty not to inflict evil, harm or risk of harm.

NUCLEOTIDE. A sub-unit of DNA or RNA, consisting of a nitrogenous base (adenine, guanine, thymine or cytosine in DNA; RNA has uracil instead of thymine). Thousands of nucleotides are linked to form the DNA or RNA.

PENETRANCE. The frequency with which persons with two recessive alleles or one dominant allele for a disorder show outward signs of the disorder. Where the frequency is less than 100 per cent, penetrance is said to be reduced.

PHENOTYPE. The appearance of an individual that results from the interaction of genes and the environment. This term is also used more narrowly to mean the observable characteristics resulting from a particular genotype.

PKU, PHENYLKETONURIA. An inherited error of metabolism resulting in the inability to convert phenylalanine in the diet to tyrosine in the body. The resulting accumulation of phenylalanine leads to mental disorder. The disorder, which is due to a defective liver enzyme (phenylalanine hydroxylase), can be diagnosed in newborns by a simple test. It can be treated with a diet low in phenylalanine.

POLYGENIC. A trait or characteristic that is determined by more than two genes acting in concert.

POLYMORPHISM. The presence in a population of two or more genetically determined forms of a trait, none of which is rare. Polymorphisms, which are useful for genetic linkage analysis, may result from changes within a gene or in the DNA between genes.

PROBE. See GENE PROBE.

PROTEIN. A molecule composed of a chain of amino acids arranged in a specific sequence that is determined by the sequence of DNA base pairs. Protein molecules determine the structure and function of living organisms.

RECESSIVE. Refers to an allele of a gene that will be expressed only if it is present in two copies, *i.e.*, on both chromosomes (compare with dominant).

RESTRICTION ENZYME. An enzyme that has the ability to recognize a specific nucleotide sequence and cut it at that sequence.

RES NULLIUS. The property of no one. A thing that has no owner, either because a former owner has abandoned it, it has never been appropriated by any person or it is not capable of private ownership.

RFLP, RESTRICTION FRAGMENT LENGTH POLYMORPHISM. A fragment of DNA resulting from cleavage by a restriction enzyme. The length of the fragment depends on whether the restriction site is present. Because these sites are polymorphic they are useful as markers in linkage studies to map the genome.

SEX CHROMOSOMES. The X- and Y-chromosomes, which are responsible for sex determination. XY individuals are male; XX individuals are female.

SICKLE CELL TRAIT. Refers to the phenotype of a person who carries one abnormal allele for sickle cell disease. It can be identified by a simple blood test. The sickle cell mutation has a high frequency in some populations that are subject to malarial infections, such as African blacks. The defective gene is thought to have been maintained in the population because it confers increased resistance to malaria on carriers, even though it kills those with a double dose of the gene. The location and the DNA sequence of the gene are now known.

SINGLE GENE DISORDER. See MENDELIAN TRAIT OR DISORDER.

SOMATIC CELLS. Any cell in the body that does not have the capacity to become a germ cell (egg or sperm).

SPINA BIFIDA. An opening in the spinal canal that is due to a developmental disorder with multifactorial causation.

TAY-SACHS DISEASE. An autosomal recessive disorder resulting in developmental retardation, paralysis, dementia and blindness followed by death, usually before the end of the third year of life. The defective gene codes for an enzyme that would normally degrade certain chemicals in the brain, leading to an accumulation of these undegraded substances in the brain and nervous tissue. The gene is found in highest frequency among Ashkenazic Jews of Eastern European origin. The location of the gene is now known.

THALASSAEMIA. Any of several heritable disorders of haemoglobin resulting from defective genes causing the reduced production of globin, a component of the haemoglobin molecule.

X-LINKED. Any gene found on the X-chromosome or traits determined by such genes.

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