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## Social capital, regional development, and Europeanisation in Hungary. A literature review

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# Genetic Information: Science, Society, and Legal Norms

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## 1. Introduction: The World of Genetic Information

The results and interpretation of the Human Genome Project, the various forms of cloning, stem cell research, genetic screening, pre-implantational tests, sex selection, and other advances in medical genetics, all challenge the existing social and cultural meanings of personal identity, reproduction, health, therapy, and family bonds. So far, the treatment of these fundamental issues has been separated into two different arenas of discussion. While scientific discourses focus on the novelty of genetic information and the medical-technological aspects of the new genetic era, other experts in the fields of the humanities and social sciences, such as philosophers, lawyers, and anthropologists, express their concerns about the social and cultural impacts of this epoch.

This book endeavors to address the issues of genetic information from a multidisciplinary perspective. With prominent biologists, medical doctors, lawyers, anthropologists, philosophers, sociologists, and theologians from different European countries and Canada among the contributors, a unique opportunity opens up for exchanging views on the complex biological and social impacts of the future proliferation of genetic information. The authors of this book explore the various uses and applications of genetic information in the biomedical sciences, in insurance, and in family law.

The beginning of the twenty-first century will be marked in human history for collecting, classifying, and interpreting genetic data, including the human genome. Most of these tasks are still ahead of us, but it is not too early to think about the ways we accumulate, store, and handle genetic data. A number of factors warrant the consideration of special protection. One is the fact that some genetic information relates to the future, thus the individuals concerned might be in a less favorable situation later than they are now. The law has arrived at a number of solutions for eliminating past and current injuries of discrimination, but the legal techniques of sanctioning prejudice against disadvantages arising *in the future* have not been developed yet.

Genetic data is precious at the individual level because, in addition to providing an exact diagnosis of an existing illness, it may also give us a glimpse of the future by showing our predisposition to certain other conditions. Although the real capabilities of science currently are far behind what expectations might have led us to believe, it is still possible that the genetic background of several diseases, but also of variations and differences among human beings and particularly between genders, will be illuminated. However, it is important to stress that we do not know much about the relationship between a person's genome and the *expression* of that person's genetic make-up. Most of the conditions that are labeled as genetic involve some environmental and even cultural factors.

Genetic data poses unique problems in handling, protecting, and using information.<sup>1</sup> Even the term 'genetic data' in itself is difficult to define. Certain family medical records can also be qualified as such, but so can predispositions to diseases or monogenic disorders (that is, disorders caused by the lack of, or error in, a single gene). The lack of precision in defining genetic data also makes it difficult to establish clear rules for handling of these data. Genetic data is also unique in that while other medical data is related only to one person's health status, the knowledge of this type of data potentially involves more people. David Heyd<sup>2</sup> pointed out in his classic study that unlike a traditional medical test, genetic testing and screening may affect other persons besides the tested patients. Learning of an inherited disease has a serious effect on the lives and decisions of also those family members who otherwise may not have wanted to submit themselves to testing. Once someone decides to inquire about his or her genetic make-up, it will ultimately influence other family members in their life style, reproductive and family planning, or health insurance status and decisions.

Health status based on genetic characteristics has already become an element in the public perception of health. In order to forge a better chance to have a healthy child, pre-implantation diagnosis is often suggested by doctors. Genetic diseases have special characteristics. They raise ethical considerations different from those raised by non-genetic diseases. First of all, these diseases are regarded as irreversible and more or less objective conditions. The threat of developing symptoms affects the individual's life, especially in case of late-onset diseases. Genetic anomalies may be inherited by the offspring, and consequently may effect a number of decisions concerning reproduction and health care.

1. William F. Mulholland and Amy S. Jaeger (1999) "Genetic Privacy and Discrimination: A Survey of State Legislation," *Jurimetrics Journal*, 39(3): 317–326.

2. David Heyd (1992) *Genethics: Moral Issues in the Creation of People* (Berkeley: University of California Press).

## 1.1 Lessons of Eugenism

Since the commencement of the Human Genome Project, the never-before-seen novelty of the Genetic Era has been emphasized by scientists and politicians, in public debates and in the media. However, to determine what is really new is always a confusing question. One may refer to different episodes of eugenism<sup>3</sup>, which since the times of antiquity have provided numerous examples for the use of genetic enhancement, even if under the current state of science we would not necessarily call these practices genetic-based enhancements.

These historical episodes demonstrate that inheritable characteristics, even in the total absence of scientific evidence, often served as a basis for various forms of discrimination,<sup>4</sup> as well as for eugenic sterilization, selective killing, and other injustices that later were regarded as crimes. In 1927 Justice Holmes delivered the infamous verdict that “it is better for all the world, if instead of waiting to execute degenerate offspring for crime, or let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the fallopian tubes. Three generations of imbeciles are enough.”<sup>5</sup> No wonder that fears of eugenism still play an important role in the public understanding of genetics.

Among the natural sciences, the history of biomedical research is especially burdened by examples of risky and hazardous interventions. It is equally important to note, however, that the different eugenic episodes in biomedical thought and practice were often supported by sympathetic branches within the social sciences, as both were influenced by the same general discourse. The mentally ill were sterilized; newborn babies with disabilities simply did not receive medical treatment. Still, despite the regrets that followed the tragedies, despite the acknowledgement of misconceptions and mistakes, nothing could hinder the continuation of scientific discoveries and nothing could tame human curiosity.

3. Much before Nazism, a different form of eugenism appeared frequently in the social sciences. The Frenchman Arthur de Gobineau published his work on the inequality of races in 1853. He considered the relevance of blood as of utmost importance not only on a family level but also on the level of the entire nation. He thought that *métissage* or *mélange des sangs* could lead to degeneration of the whole nation. In 1902 the Englishman Archibald Garrod pointed out that certain diseases appear soon after birth and therefore can be regarded as inherited. For more details, see Catherine Bachelard-Jobard (2001) *L'eugénisme, la science et le droit* (Paris: Presses Universitaires de France).

4. During its early history, United States immigration policy excluded certain populations from entering the country, for instance the Chinese between 1882 and 1902. Then in 1924 the American Immigration Act was clearly based on the principle of preserving racial purity.

5. *Buck v. Bell* (1927) 274 U.S. 200.

If one examines the chronicle of these human tragedies it can be observed that a specific form of reductionism, namely ‘biologism’ played a crucial role in the process. Biologism, or the naturalization of social and cultural differences, became a central part of social ideologies as well, further reinforcing the taken-for-granted nature of these scientific practices. Of course, by looking at the roots of this research one can easily see that *unethical* scientific research was also *bad* scientific research. The other conclusion, which can be illustrated by numerous episodes of the eugenic movement, is that bad science was reinforced by bad social science and consequently legitimized legal norms that were later regarded as unconstitutional. The abuses that were investigated by lawyers in the Nuremberg trials later were interpreted by scientists as examples of bad science and were considered as severe violations of human rights as well.

Even the more recent history of medical research reveals a disturbing pattern of discrimination against racial and ethnic minorities, and against women. And this indicates that the frontiers between science and law are not self-evident. The formulation of research and control groups are regarded as part of the scientific method, although these categories may be culturally, morally, or legally problematic. This is why it is crucial that there be communication between various disciplines on theoretical and methodological issues. In one infamous example, a research project was both discriminatory and scientifically unsound. In the *Tuskegee Study*, which ran from 1950s until the early 1970s, researchers studied the effects of untreated syphilis in a group of African-American men. The researchers never disclosed to the research subjects that they continued to suffer from a treatable but serious illness. The researchers were able to study the long-term effects of infection with syphilis by withholding treatment from the research subjects.<sup>6</sup>

Examples can also be found of biological prejudices when otherwise relevant scientific information leads to severe mistakes in social policy simply because of adopting a scientific paradigm in a broader area without testing the verity of the extension. In 1965 researchers found a high prevalence of the *karyotype XYY* among prison inmates in Britain. Many people, scientists and laymen alike, quickly took this finding to justify the link between an extra Y chromosome and a tendency to hyper-aggressivity and violence. This assumption was rejected by genetic researchers, but still resulted in an enduring popular belief. Some other authors believe that the increased risk of arrest or conviction may stem from increased likelihood of getting caught.<sup>7</sup> This story

6. David J. Rothman (1982) “Research Ethics and Social Deprivation: Were Tuskegee and Willowbrook ‘Studies in Nature?’” *Hastings Center Report*, 12(2): 5–7.

7. David Wasserman and Robert Wachbroit (2001) “Introduction: Methods, Meanings, and Morals,” in David Wasserman and Robert Wachbroit (eds.) *Genetics and Criminal Behavior* (Cambridge: Cambridge University Press), p.9.

is an eloquent example of the interrelation of bad science and bad social (criminal) policy.

If one looks at the cases of scandals and abuses in science, one can notice that not only ethical problems arose but also scientific usefulness was questioned. Consequently, if basic ethical values are compromised we can not talk about good science. In other words, science is and must be a multidisciplinary enterprise today.

Multidisciplinarity also involves a stronger emphasis on ethical and legal norms. After the Second World War, as a result of the Nuremberg trials, German doctors and scientists were held liable for their abuse of human subjects in biomedical experiments. The Nuremberg Code declared the necessity of *voluntary consent* and disclosure of the general nature of the experiment. The principles of conducting research on human subjects were further developed in the Helsinki Declaration in 1964.

The significance of bioethics, as well as the combination of the freedom of research principle and the necessary legal restrictions, are best illustrated today by the Council of Europe's Convention on Human Rights and Biomedicine.<sup>8</sup> By adopting this Convention in 1997, the Council of Europe established the most important ethical norms for biomedicine. The Convention has been supplemented by a number of additional protocols since then, dealing with issues of cloning and transplantation. The Charter of Fundamental Rights can also be regarded as a safeguard in the field of life sciences and biotechnology. The European Union and the various European states have, over the course of the past decade, adopted directives and passed laws that prove an enduring commitment to protect fundamental values in the field of biomedicine and biomedical research.<sup>9</sup>

### *1.2 The Advent of the Genomic Era*

When on the twenty-sixth of June in 2000, the leaders of the public Human Genome Project and the private company Celera announced completion of the 'working draft' of the human genome sequence, the dominant attitude was of scientific pride and enthusiasm. The results of this historically relevant project and the analysis of the human genome were published by the public project on February 15, 2001 in the magazine *Nature* and by Celera Genomics on February 16, 2001 in the magazine *Science*.

8. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164). Signed in Oviedo, April 4, 1997. See the Appendix of this volume, and for the official text: <http://conventions.coe.int/treaty/en/treaties/html/164.htm>.

9. For more details, see the Appendix.

Since the beginnings of the genome projects, the key application of human genome research has been to find *disease genes*. The genome sequence has also helped to reveal the mechanism that may lead to some chromosomal deletion syndromes. Consequently more accurate and timely diagnoses can be made and hopefully better therapies can be developed. The other important domain is the *pharmaceutical use of genetics*: based on our newly acquired genetic knowledge, the pharmaceutical industry is now heavily focused on developing a limited set of new drugs. The knowledge of the complete set of human genes and proteins will greatly expand the search for suitable new drug targets.

The *medical use* of the genetic information, inasmuch as it only serves healing, is rather easily morally justified. Medical intervention aimed at curing ill children or cancer patients (for example), even if this demands gene therapy, is easier for the public to accept than scientific research that does not offer the immediate hope for medical application, or the use of genetic information in other spheres of life. The public is much more wary of the use of genetic information for *non-medical, non-research* purposes, and the law is also likely to set much stricter standards for the use of genetic knowledge here. It is precisely because of these unique concerns that this volume will focus primarily on the use of genetic information *outside* healthcare, and on unusual applications beyond traditional medical treatment.<sup>10</sup>

We should note here that one of the major dilemmas in contemporary bioethics is whether one should distinguish between therapy and enhancement. Francis Fukuyama, who is a member of President Bush's Council on Bioethics, tries to defend the separation between the two in his book titled *Our Posthuman Future*.<sup>11</sup> Drawing moral distinctions between treating patients and enhancing their characteristics is not only an ethical and philosophical issue, it is also preeminently relevant for legal policy makers. This is why we turn to a discussion of the ethical and legal questions involved in genetic research and in the various uses of genetic information.

## 2. Ethical and Legal Questions

In the legal regulation of scientific activities and developments, law usually reacts to the actual social potential of science. However, in addition, it also takes an overview of the basic ethical norms affecting future risks, basic rights and social values,

10. Jean-René Binet (2002) *Droit et progrès scientifique. Science du droit, valeurs et biomédecine* (Paris: Presses Universitaires de France).

11. Francis Fukuyama (2002) *Our Posthuman Future: Consequences of the Biotechnology Revolution* (New York: Farrar, Straus and Giroux).

health policy, and scientific research, and then attempts to develop legal norms based upon these. But legal changes have been much more limited in scope than is required by the pressure for innovation in science. If a new technical or scientific development arises, the reaction of legal thought is likely to tend towards an incorporation into the already existing legal principles and analysis, rather than to the development of new legal institutions. Reluctance of legal innovation is related to the need for coherence within the legal system and that is often one of the major guiding forces of new legal policies. Furthermore, internal coherence of the legal system is one of the most important guarantees for the principle of justice.

Moving to the field of genetic information, the development of new, genetics-based medical treatments, the monitoring of genetic data, genetic testing and screening, the establishment of genetic databanks, all have impact on fundamental legal questions, such as the equal treatment of individuals, privacy, and access to health care.<sup>12</sup> The new genetic knowledge we face now affects essential human conditions: our family relations, our reproductive decisions, but also more specific domains, such as insurance, labor relations, and intellectual property rights.

As more and more genetic information is produced and its uses become increasingly widespread, complex legal questions of data protection emerge. This is partly because the human DNA has a symbolic significance. Furthermore, as already mentioned above, the term ‘genetic data’ may not be so easily defined.<sup>13</sup> Genetic data may be obtained from DNA and chromosome analyses and certain clinical tests, as well as from traditional sources of genetic information, such as family history.<sup>14</sup> One of the most problematic features of genetic characteristics is that they may be inherited by the offspring, and it may affect the individual’s health status and his or her spouse’s chances of having a healthy child. In terms of causality, one may make a distinction between the type of genetic information that is produced by genetic tests for monogenic recessive or dominant conditions where degrees of risk are high, and the

12. Bertrand Mathieu (2000) *Génome humain et droits fondamentaux* (Aix-en-Provence: Presses Universitaires d’Aix-Marseille).

13. The British Human Genetics Commission defines the notion of “personal genetic information” as “information about the genetic make-up” of an identifiable person, whether derived directly from DNA (or other biochemical) testing methods or indirectly from any other source. See Human Genetics Commission (2002) *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (London: HGC), p.25. And the website <http://www.hgc.gov.uk/insideinformation/iichapter1.pdf>.

14. *Genotype information* that involves the analysis of the DNA provides very detailed information about the individual and about inherited characteristics. The *phenotype information* does not require the direct examination of the DNA, sometimes it is observable through physical examination (e.g. eye color). The third type of genetic information is the *family medical history*, which can show certain patterns of inheritance. See Human Genetics Commission, *op. cit.*, p.26.



type that can be derived from testing as susceptibility data. In this latter case, genetic information is not only an indicator of one individual's current state of health; it is also an indicator of that individual's likely future health.<sup>15</sup>

Specific legal definitions and interpretations of genetic data have already appeared in numerous international legal documents.<sup>16</sup> It is acknowledged in them that genetic information may be gained secretly (without the acknowledgment of the individual) and from a very small amount of material. Due to the stability of the DNA it can be recovered from stored material or even from archaeological deposits. Genetic information reveals not only the actual health status of the individual, but it also has a predictive value. Genetic information may tell a lot about the biological origin of the individual, including paternity information.<sup>17</sup>

The particular legal treatment of genetic data goes beyond the conceptual problems of genetic information. Legal philosophy and policy-making now focuses primarily on the various *uses* of genetic data: in making a diagnosis, in the health care of family members, in biomedical and other research, in setting up biobanks, in public health care, in forensic applications, in insurance and employment.

Before analyzing the handling of genetic information in specific biomedical and non-medical domains, two legal principles need to be analyzed: the principles of *privacy* and of *non-discrimination*.

### 3. The Principles of Privacy and Non-Discrimination

#### 3.1 Privacy and Genetics

Mark Rothstein applies the metaphor of the 'secret' in explaining the relevance of the genetic revolution after the completion of the Human Genome Project. "Before the last half of the twentieth century, human genetic secrets belonged exclusively to

15. For medical conditions controlled by a single gene (such as Huntington's disease), the indication can be precise. For medical conditions that involve a more complex combination of genes or environmental factors (such as heart disease), the indication might involve only an increased probability that a future medical problem may arise.

16. UNESCO Universal Declaration on the Human Genome and Human Rights (1997); Council of Europe, Recommendation No. R (92) 3 on Genetic testing and Screening for Health Care Purposes (February 1992); WHO, Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services (1997).

17. More about the relevance of genetics in a paternity case can be seen in the *Mikulic v. Croatia* case (ECHR Case No. 53176/99, Judgment No. 074a(2002), dated February 7, 2002). See the press release at [http://press.coe.int/cp/2002/074a\(2002\).htm](http://press.coe.int/cp/2002/074a(2002).htm) or the full judgment at <http://hudoc.echr.coe.int/Hudoc2doc2/HEJUD/200210/mikulic - 53176jv.chb1 07022002e.doc>.

nature, they were locked securely within the genes . . . Today the concern has shifted to a different type of genetic secrets. The secrets no longer belong solely to nature. Some belong to humans as well.”<sup>18</sup>

Right to privacy usually refers to the control over someone’s *own* personal information. Genetics has opened a vast field of research on individual genetic characteristics, which has expanded access to personal genetic information, destabilizing our traditional notions of privacy. Genetic screening and testing,<sup>19</sup> in particular, undermine the individual-based concept of privacy in at least two respects. First, genetic screening of one individual may affect not only close family members, but also relatives who do not even have regular contact, who may have different religions and different levels of education, and might live in distant places, even in different societies. Second, genetic testing and screening does not really constitute a right to decide. When the results of testing or screening are disclosed to adults, the treatment of genetic disorders may often be impossible or the solution offered in those cases are not regarded as therapy at all. In case of prenatal testing, the only ‘treatment’ available is a genetically induced abortion. In case of pre-marriage testing, the ‘treatment’ is not to get married or not to have children if, for instance, both parents turn out to be carriers of a disease gene. It follows that an individual’s control over his or her personal information should be guaranteed during the entire course of her medical consultation and examination. This control includes the right not to know and the right to avoid those tests where no therapeutic advantage can be offered.

Genetic testing may often have life-long relevance as genetic data can effect a person’s lifestyle, future plans, partner choice, plans for children, career choice, and even educational ambitions. The question from a legal standpoint is thus how genetic data should be protected and used.<sup>20</sup>

18. Mark A. Rothstein (1997) “Genetic Secrets: A Policy Framework,” in Mark A. Rothstein (ed.) *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven and London: Yale University Press), pp.451–495.

19. The American Task Force on Genetic Testing, a joint working group of the Department of Energy and the National Institutes of Health, has offered a working definition of a genetic test. The definition restricts genetic testing to processes which are carried out for the direct analysis of human DNA and other compounds such as RNA, chromosomes, proteins and certain metabolites, with a view to achieving a number of clearly identified end points; namely, the prediction of inherited disease, the detection of carrier status or the diagnosis of actual inherited disease. This can encompass not only the testing of individuals but also the screening of at-risk populations, and will include prenatal and antenatal screening and the testing of families with recognized histories of genetic disease. For more, see the website <http://www.hopkinsmedicine.org/tfgetels/fedregister/index.html>.

20. Wolfram Henn (1999) “Genetic Screening with the DNA Chip: A New Pandora’s Box?” *Journal of Medical Ethics*, 25(2): 200–203.

I believe that a unique legal status must be afforded to genetic data<sup>21</sup>, for it is *not only health data*, but also can be used to *identify the individual*. This complex characteristic of genetic data requires a specifically designed confidentiality regulation. Moreover, potentially unlawful access should be eliminated and the individuals' own access rights should be reaffirmed. The health care institution or the research staff can easily process genetic data. Therefore the individual should have a right to know that a test is going to be performed on him or her, but nevertheless the affected individual should be allowed to refuse to know the test results. In other words, the individual should have 'a right not to know'.

Another significant difference between genetic data and traditional medical data is that besides providing insight into the health of the individual examined, genetic data may also indicate the medical conditions of the family members of that individual, among them even unborn babies. Thus we could say that certain affected individuals might not even know of the existence of health data related to them. The genetic tests for diseases like Huntington chorea or cystic fibrosis involve a mutation in a single gene. It means that if someone inherits the mutation, he or she will certainly get the disease. Other available tests may reveal diseases, such as Alzheimer's disease, that are caused by mutations in more than one gene. These pose different problems since the test result may reveal only that the individual is susceptible to the disease, but it is not certain that he or she will get it.

There is a general belief that we consider all medical information to be private, and genetic information is not an exception in this respect. This notion starts to be problematic if we regard the fact the genetic information is obtained not necessarily through an individual DNA testing but often together with the analysis of the family medical history. However, closer observation of public attitudes towards genetic information may challenge this general view. While most people would insist on the confidentiality of traditional medical information, especially the information about some physical or mental disability, it may not be the case with genetic information.

Although there is as yet no internationally accepted comprehensive legal solution to the unique data protection problems raised by genetic information handling, the beginnings of one can be recognized. The suggestion made by a Canadian commis-

21. Specific status was guaranteed to genetic data in the International Declaration on Human Genetic Data, adopted by the UNESCO in October 2003. (For the official text of this document, see the Appendix.) For different analyses of the special relationship between right to privacy and the protection of genetic data, see Marie-Isabelle Malauzat (2000) *Le droit face aux pouvoirs de données génétiques* (Aix-en-Provence: Presses Universitaires d'Aix-Marseille); and José Antonio Seoane Rodríguez (2002) "De la intimidad genética al derecho a la protección de datos genéticos. La protección iusfundamental de los datos genéticos en el derecho español (A propósito de las SSTC 290/2000, de 30 de noviembre)," *Revista de derecho y genoma Humano* (Bilbao), 16: 71–105.

sioner concerned with the right to privacy in 1995 was particularly significant. He offered that the goal of genetic data collection should be communicated to the person affected even if the Privacy Act does not so prescribe.<sup>22</sup>

The Human Genetics Commission (HGC), the UK's genetics watchdog, has published a report titled *Inside Information: Balancing Interests in the Use of Personal Genetic Data*.<sup>23</sup> It contains proposals as to in what circumstances a person's personal genetic information should be open to use and by whom, and in what circumstances this information should be protected from outside use. The HGC report recommends that obtaining, testing or storing someone's DNA without their knowledge or consent should become a crime, except as allowed by the law for forensic purposes. It also says that employers should not insist that employees take genetic tests as a condition of employment or promotion; insurers should not use the results of genetic tests for their own benefit; and that no one should be unfairly discriminated against on the basis of his or her genetic characteristics. According to the HGC, medical research should be allowed to use genetic information, while ensuring that those individuals are protected whose genetic information is stored in medical databases, such as in the UK Biobank. Databases established for medical or research purposes should not be used for any other purpose, including access by the police. All such databases should be overseen by an independent body, such as an ethics committee.

Genetic information and privacy pose so many new legal dilemmas that *genetic privacy* has become a *terminus technicus* to refer to the specificity of legal problems related to the question of how to maintain control over the genetic information of the individual.<sup>24</sup>

### 3.2 *The Prohibition of Genetic Discrimination*

The ethicist Thomas Murray described human genetics as a "science of inequality: a study of human particularity and difference."<sup>25</sup> Indeed, the danger of genetic discrimination exists in several spheres of life, but the recognition of such discrimination is not as easy as it is, for example, in the case of racial discrimination. The same person who, because of a definite personal attribute, is a member of a genetic minority,

22. See The Privacy Commissioner of Canada (1995) *Genetic Testing and Privacy* (Ottawa: Ministry of Supply and Services), at the website [http://www.privcom.gc.ca/information/02\\_05\\_11\\_e.pdf](http://www.privcom.gc.ca/information/02_05_11_e.pdf).

23. See footnote 14, and the report at <http://www.hgc.gov.uk/insideinformation/index.htm>.

24. One of the most comprehensive treatments of this complex field has been published by Graeme Laurie. See Graeme T. Laurie (2002) *Genetic Privacy: A Challenge to Medico-Legal Norms* (Cambridge: Cambridge University Press).

25. Thomas Murray (1992) "Genetics and the Moral Mission of Health Insurance," *Hastings Center Report*, 22(6): 12–17.

might from another point of view belong to the genetic majority. At the same time, belonging to a minority might give rise to positive social discrimination, as in the case of a rare but beneficial genetic attribute.

Throughout history people have been segregated on basis of race, sex, religion, and ethnicity. With the recent emergence of genetic screening and genetic engineering, a new form of potential discrimination has appeared: discrimination based on genotype. This type of discrimination may occur in health care services, and in the fields of life insurance policy, labor law, reproductive rights, family law, and so on. Genetic discrimination is especially problematic, as not only diseases but also certain human characteristics and abilities have a genetic component. The danger with this development is that genetic discrimination potentially involves overall discrimination.

Discrimination on the basis of genetic attributes, however, differs from previously known types of discrimination in that although these attributes are insurmountable, they are for the most part *invisible*. If these conditions of an individual become public, uncertain and unpredictable prejudice may arise against the affected individual, and this unpredictability allows for abuses. Another possible effect of the abundance of genetic knowledge can be that if some genetic traits are significantly more common in a certain ethnic group, then the exclusion of this trait from an insurance contract, for instance, may result in a new form of indirect, ethnic discrimination.<sup>26</sup>

Moreover, difficulties might emerge concerning the *time dimension* of genetic information: while in comparison with a traditional disease, which may prevent someone from fulfilling a job in the present, a genetic predictive test may reveal a probability to develop the disease in the future, and thus a looming loss of capacity to work. As genetic discrimination may differentiate between people based on predictions of a future handicap, it can be regarded as a *new form* of discrimination since the classical grounds for discrimination refers to present or past disadvantages.

Genetic data, as a form of prognostic information, has a *financial value*. Although commercialization does not necessarily lead to discrimination, the processes by which economic interests may generate discrimination should be carefully scrutinized. Thus, we need to consider which diseases are regarded as priorities in medical, pharmaceutical research, who should be offered, and what sort of genetic testing.

There is another form of discrimination that may occur in the use of genetic data. Most people know what to make of the results of, say, a blood sugar test. However, data coming from a genetic test is much more complex; its reading and interpreta-

26. In 2000 the European Parliament accepted a resolution to propose a directive that would include the prohibition on the use of personal medical data such as genetic data to enable insurers to act in a discriminatory way.

tion requires special expertise. Therefore it can be foreseen that there will be groups of individuals who are less likely to be able to get access to genetic counseling and even if they have access they may lack the necessary education to understand the information. As a consequence, they will suffer an additional form of discrimination that is the *discrimination in the accessibility* of sensitive and complex medical data.

The European Union was surprisingly quick to include genetic discrimination among the traditional forms of discrimination prohibited under the Charter of Fundamental Rights.<sup>27</sup> However, if we examine the notion and the existing jurisprudence of discrimination we may not find the concept of genetic-based discrimination so evident. Perhaps the only stable element of this form of discrimination that is supported by consensus is that racial, ethnic, and national minorities should not suffer further discrimination by genetic tests.

Fear of discrimination, of course, is not a sufficient reason to reject the scientific knowledge gained from biomedical and genetic research, such as the Human Genome Project. What is at stake is, rather, how one can avoid the discriminatory effects of the project and how our genetic interventionism can be tamed and used for good purposes.

#### 4. Using Genetic Data for Research Purposes

While general data protection norms specify the *medical use* of health care data, *research purposes* are regarded as distinct from the preventive and therapeutic uses. In Article 2 of the Convention on Human Rights and Biomedicine,<sup>28</sup> it is stated that “The interests and welfare of the human being shall prevail over the sole interest of society or science.” It also follows from the European Union data protection directive<sup>29</sup> that data collected and processed for preventive treatment, diagnosis, or specific research purposes may only be used in the manner that is specified.

27. Article 21 on Non-Discrimination in the Charter of Fundamental Rights of the European Union states that “Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.” For the official text, see *Official Journal of the European Communities*, C 364, 18.12.2000, p.9, at [http://www.europarl.eu.int/charter/pdf/text\\_en.pdf](http://www.europarl.eu.int/charter/pdf/text_en.pdf).

28. See footnote 9.

29. Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of Such Data. For the official text, see *Official Journal of the European Communities*, L 281, 23.11.1995, pp.31–50, at [http://europa.eu.int/comm/internal\\_market/privacy/docs/95-46-ce/dir1995-46\\_part1\\_en.pdf](http://europa.eu.int/comm/internal_market/privacy/docs/95-46-ce/dir1995-46_part1_en.pdf).

When personal data has to be used it is not satisfactory to claim that the data will be used ‘for research purposes’. The aims of the research should also be explained. Another problem may arise when further or different uses of already archived samples and tissues are demanded. Obtaining valid and informed consent is often problematic in this case. Sometimes the mere disclosure of the names of the sources might be a violation of their privacy rights.

In clinical practice it is often difficult to separate the therapeutic and research use of tissues and the related health data information. Therefore, in some countries, there is an explicit prohibition on using data that had been collected for the purpose of diagnosis and therapy for research purposes. Concerns for data protection and the separation of various uses of sensitive personal information are important legal concerns, and not only in Europe. For instance, according to Article 22 of Quebec’s Civil Code,<sup>30</sup> no part of the human body (including, organs, tissue or substances) taken from a person during the course of therapy can be used for research if the concerned individual did not consent to it.

National bioethics commissions in many countries have tried to grapple with the dilemmas of how to obtain valid consent for multiple research projects and what are the acceptable guarantees for data protection in the field of research. In 2000, the Bioethics Committee of the Japanese Council for Science and Technology adopted the “Fundamental Principles of Research on the Human Genome.” In the document, Principle 12 deals with the “leakage of personal information.”<sup>31</sup> The United Kingdom Human Genetics Commission proposed in its above quoted report that a *general consent* is acceptable if the genetic data used in research has already been anonymized.<sup>32</sup> The Estonian Genome Project introduced the concept of *open consent*. Open consent refers to the fact that under the Estonian Human Genes Research Act individuals consent to become general gene donors. As many of the specific research applications are not yet known and cannot be specified in the consent form, therefore, it covers genetic research in a broad sense. In addition to this, in the Estonian model, gene donors cannot provide partial or conditional consent.

30. Adopted in December 1991.

31. “Research institutions and researchers should take necessary measures in order to prevent the leakage of personal information. In the event of the leakage of personal information, firm disciplinary measures, including demotion, should be taken against the person(s) who leaked the information, the researchers undertaking the said research, the custodians of the personal information, the director of the research institution and other personnel associated with the leaked information. Any individual whose personal information is leaked or who sustained damage from the said leakage is legally entitled to receive compensation or indemnity.” (Official translation from Japanese.)

32. Human Genetics Commission, *op. cit.*, p.95.

## 5. From Assisted Reproduction to Cloning

Perhaps there is no other field in which the development of the interaction between science, ethics, and law has been as socially significant and politically charged as in the case of reproduction. Assisted procreation provided a unique opportunity for biomedical research, but at the same time created new ethical dilemmas concerning such issues as the use of pre-implantation genetic tests. Starting with the technical possibility of medically assisted reproduction, we have, practically without noticing it, achieved a demand for sperm and egg donors. Then through the 'micro manipulation' of sperm (intracytoplasmic sperm injection, ICSI) we have come to the first artificial reproduction. In the end this process has brought us to the reproductive technique now considered scandalous, in which just one single reproductive cell, an egg, plays a role. Observing this development, the question arises: if the new techniques that separated procreation from sexuality and have been so easy for the public to accept, then why is cloning so different?

It is notable how easily public opinion sailed through all these enormous changes, and without particular hesitation accepted the fact that now not every child is born through natural reproduction, and that pregnancy is not always induced in 'a natural way'. Most regulations on reproduction in Europe have effected a belief that the procedures are a sort of *quasi* medical treatment to assist infertile partners who could not have children naturally, and for whom infertility treatment has proven to be ineffective.<sup>33</sup> The role of assisted procreation and embryo research in the genetic era was also recognized by Jürgen Habermas in his recent book titled *The Future of Human Nature*<sup>34</sup>. He envisages the development of liberal eugenics as a result of autonomous choices made by individuals for selection rather than just a request for therapy in the field of biomedicine. This trespassing of the frontiers between therapy and selection<sup>35</sup> will reinforce the cultivation of the increasingly medicalized choices that will create a new and extensive domain of biomedical interventions. As a result of these choices, liberal eugenics will affect not only the individual who makes the choice but also interpersonal relationships.<sup>36</sup> "The irreversible choice a person makes for the desired makeup of the genome of another person initiates a type of relationship between

33. Philosophical issues related to infertility and rights are elaborated in a recently published book: Mary Warnock (2002) *Making Babies: Is There a Right to Have Children?* (Oxford: Oxford University Press).

34. Jürgen Habermas (2003) *The Future of Human Nature* (Cambridge: Polity Press). For the original German version, see Jürgen Habermas (2001) *Die Zukunft der menschlichen Natur. Auf dem Weg zu einer liberalen Eugenik?* (Frankfurt am Main: Suhrkamp).

35. For instance sex selection of the future child and pre-implantational selection of certain characteristics.

36. Habermas, *op. cit.*, p.63.



these two which jeopardizes a precondition for the moral self-understanding of autonomous actors.”<sup>37</sup> The procreator becomes a creator.

‘Creation’ can be exercised now in numerous forms in the *in vitro* clinics. One of the most recent and ethically contested technique was the *in vitro* ‘treatment’ of using two eggs from two different ‘mothers’. In March 2002, the monthly journal *Human Reproduction* announced a report on a research project,<sup>38</sup> which made it clear that some reproductive medical scientists do apply gene therapy, even though it had been strongly condemned on ethical grounds. The researchers stated that genetic modification had been used in the ‘test-tube baby program’ to eliminate those individual characteristics of sterile women’s eggs that were disadvantageous from the standpoint of conception. Therefore they introduced certain mitochondria to the eggs that originated from another mother.

The ethical concerns focused on the participation of two mothers in a single reproductive procedure. The participation of more than two people in reproduction, however, is an inherent part of reproductive medicine. Extra-body, *in vitro* fertilization makes it possible to implant the embryo into a body different from that of its biological mother,<sup>39</sup> to use sperm from an anonymous donor, and not from the father, or to fertilize the egg of an anonymous donor, and not one from the mother.

Since the birth of the first test-tube baby in 1978<sup>40</sup> reproductive medicine has developed several multiple-parent models for the ‘treatment of infertility’. Thus, the family palette has become even more colorful, and now in addition to natural parents, adoptive parents, blood parents and foster parents, the term ‘genetic parents’ has

37. *Ibid.*

38. Jason A. Barritt and his colleagues reported the technique of using two eggs and that has led to the birth of 30 babies. See Jason A. Barritt, Steen Willadsen, Carol Brenner, and Jacques Cohen (2001) “Epigenetic and Experimental Modifications in Early Mammalian Development, Part II: Cytoplasmic Transfer in Assisted Reproduction,” *Human Reproduction Update*, 7(4): 428–435, at [http://www3.oup.co.uk/humupd/hdb/Volume\\_07/Issue\\_04/pdf/070428.pdf](http://www3.oup.co.uk/humupd/hdb/Volume_07/Issue_04/pdf/070428.pdf).

39. In a settlement of a surrogate pregnancy case in California, *Johnson v. Calvert*, the egg-donating genetic mother demanded that the motherhood of the baby be determined by the court, as did her daughter who bore the baby. To complicate the matter both demanded a genetic determination of motherhood. Both parties supported their claim with medical opinion. Mark and Crispina Calvert established a surrogate motherhood contract with Anna Johnson to bear their baby. After birth, however, both mothers were determined to have the baby on the basis of blood. Each mother supported her case with expert medical opinion, and ‘proved’ their ‘natural’ motherhood based on differing points of view. See *Johnson v. Calvert* (Ca.1993) 851 P.2d 776, 790 and also [http://philosophy.wisc.edu/streiffer/BioandLawF99Folder/Readings/Johnson\\_v\\_Calvert.pdf](http://philosophy.wisc.edu/streiffer/BioandLawF99Folder/Readings/Johnson_v_Calvert.pdf).

40. Although the development of various techniques of *in vitro fertilization* (IVF) and embryo transfer (ET) started after the second world war, nevertheless the first baby who was born as a result of this technology was Louise Brown. After her birth in 1978, reproductive techniques revolutionized the ‘treatment’ of infertility.

appeared, and we now have egg donors, sperm donors, and ‘just’ surrogate mothers. If we add embryo donation to the list, we have four new cases of parenthood, three of which are genetic.

With this acceleration in the technological development of assisted procreation, the possibility of human reproduction by cloning has become more than a theoretical one. Some thirty years ago James Watson, one of the describers of the double helix of DNA, already suggested the prohibition of cloning human beings. At that time, nobody took his warning seriously. The situation changed overnight when the little sheep created through cloning, Dolly, became a press sensation all over the world. President Clinton, with surprising speed, banned the use of federal funds on human cloning.

George Annas, the American bioethicist, made a noteworthy remark about Dolly. He felt that the lamb generated a surprising amount of public outrage, even among scientists, because in contrast to the mass of genetically modified animals she was named Dolly, and thus gained a personality. After all, in the original scientific announcement she was still not given a name—the cloned lamb was only called ‘Number 6LL3’. In addition to being evocative of a toy ‘doll’, a sort of admission of willingness to take responsibility for her appeared, for in contrast to the monster created by Dr. Frankenstein, she was given a name.<sup>41</sup>

A unique aspect of the cloning debate is that artistic imagination was enthralled by the technique long before it was possible to pursue. Perhaps this is precisely why the majority of fears and threats are not related to what is truly possible to achieve now. We have not been able to clone a human yet, even if from time to time a scientist eager for fame makes the attempt. Not long ago yet another form of embryonic stem cell research failed. If in the future the so-called ‘therapeutic cloning’ succeeds, it is good to know that this does not mean that we will necessarily be able to, or even want to use the technique to implant any particular ethical or emotional characteristics into the embryo—that is, to produce cruel or angelically good people. Besides this, cloning for reproductive purposes is not permitted in North America, Japan, or Europe.

Since 2001 the public debate over reproductive cloning has strongly tended toward debate on stem cell research<sup>42</sup>, and other therapeutic cloning techniques. The first breakthrough was signaled by the debate on embryo cloning in Britain, which

41. For more about the cloning debate, see Leon R. Kass and James Q Wilson (1998) *The Ethics of Human Cloning* (Washington, DC: The AEI Press).

42. For one of the most comprehensive record of this discussion, see Suzanne Holland, Karen Lebacqz, and Laurie Zoloth (eds.) (2002) *The Human Embryonic Stem Cell Debate: Science, Ethics, and Public Policy* (Cambridge, MA: MIT Press).

has been further stimulated by the Human Fertilisation and Embryology Act passed in 1990.<sup>43</sup> For the first time a question was raised whether the research on human embryos can be extended for harvesting of surplus embryos for stem cell research. British researchers hope that the permission granted for this research will enable them to find treatments for Parkinson's and Alzheimer's disease, and for certain types of diabetes. The law is only valid for stored embryos that would not otherwise be used, and experiments are strictly to be pursued only within 14 days of conception. Therapeutic cloning, which I will not deal with here in detail, is being pursued to produce organs and tissue and not to make a copy of a human being. Since through this technique it appears that not only embryonic cells, but also adult cells can be used, the major legal concern is not the protection of embryos, but rather the need to eliminate abuses in the enormous trade in stem cells.

Most frequently the protection of human dignity and human individuality is brought up as an opposition to human cloning. The uniqueness of each individual as an individual is not, however, a universal value. Moreover, people are not only biological and genetic beings, but are also connected to society through unbreakable bonds that strongly determine their characters: factors such as their upbringing, their environment, the age in which they are born. Among other things, theoretical issues such as these had to be struggled with at all international forums that decided to stop human cloning.

Not by chance, the first Additional Protocol to the Oviedo Convention was on the Prohibition of Cloning Human Beings.<sup>44</sup> The Protocol is categorical, but the reasoning evoking the ban is not made clear by its text. Article 1 declares that “[a]ny intervention seeking to create a human being genetically identical to another human being, whether living or dead, is prohibited.”<sup>45</sup> The Protocol determines ‘genetically identical’ to mean that two human beings share with each other the same nuclear gene set: the nuclei of the cells contain identical genetic material. Thus cell and tissue cloning is not banned by the Protocol. Article 11 of UNESCO's Universal Declaration on the Human Genome and Human Rights also bans cloning for *reproductive* purposes, as it is “contrary to human dignity.”<sup>46</sup>

43. For the official text, see [http://www.hms.gov.uk/acts/acts1990/Ukpga\\_19900037\\_en\\_1.htm](http://www.hms.gov.uk/acts/acts1990/Ukpga_19900037_en_1.htm).

44. Additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, on the Prohibition of Cloning Human Beings (ETS No. 168). Signed in Paris, January 12, 1998. See the Appendix of this volume, and for the official text: <http://conventions.coe.int/treaty/en/treaties/html/168.htm>.

45. *Ibid.*, Article 1.

46. Universal Declaration on the Human Genome and Human Rights, adopted unanimously and by acclamation on November 11, 1997 by the 29th session of the General Conference of the UNESCO. See the Appendix for the official text.

As long as the development of the embryo was hidden deep in the womb until the moment of birth, philosophical<sup>47</sup> and theological approaches dominated the formation of normative concepts regarding reproduction. Since we became capable of observing the embryo with ultrasound, and by learning its sex were even able to give it a name, our normative ideas about reproduction have started to be formulated in biological terms.<sup>48</sup> But this is not always successful, and I believe it is not even desirable in every case. We may consider the embryo brought about by cloning to be simply a human being who is born as a result of a ‘single-gamete, sex-free reproductive procedure’. But we should not forget that while this latter, euphemistic qualification is biologically correct, it does not necessarily supply us with effective legal terminology.

This is not a unique case of divergence between biological and normative terminology. According to Hungarian law, for instance, the embryo comes into existence through fertilization (literally: “every human embryo is an embryo from the moment of fertilization to the twelfth week of pregnancy”).<sup>49</sup> As it follows, the clone-embryo is not a human embryo in the legal sense, because it is not developed from a fertilized egg. But once the embryo is implanted into the mother’s womb, the law considers it to be a fetus, and thus a developing human being from the twelfth week of pregnancy.

Furthermore, the recent advances in biomedical and genetic research on the human embryo as well as the widening application of pre-implantation genetic testing raised an issue that is destined to become one of the major ethical concerns in the future. And this is the question of whether we should be allowed to use genetic knowledge for human enhancement. Pre-implantation genetic testing may reveal not only a possible lethal disease in the embryo but also some less severe conditions—some of them not even regarded as diseases but only features seen as disadvantageous for the future human being. Consequently, it is difficult to draw the line between healing and enhancement. This conceptual problem of distinguishing between prevention, therapy, and eugenic uses of genetics will soon become a matter of law and health policy.

## 6. Family and Genetic Information

The discoveries of genetics have made it imaginable and possible for a growing number of people, both parents and children, to find new evidence for biological

47. Aristotle believed, for instance, that the personality developed along with the embryo as it gained human form. He felt that this process lasted forty days in the case of men, and eighty days for women. This concept was adopted by early canon law.

48. For a comprehensive overview of the debate on the legal status of the fetus, see Jean Reith Schroedel (2000) *Is the Fetus a Person? A Comparison of Policies Across the Fifty States* (Ithaca: Cornell University Press).

49. Fertilization means the joining of two gametes. Accordingly, a cloned human being is not covered by this law.

relations in their genetic roots through establishing genetic identity. Biological evidences to support the legitimacy of social bonds between parents and children have always been called upon, but the recently emerging possibility of taking DNA tests may finally reveal the truth for those who want to know it. And so far DNA paternity tests are regarded as the most reliable tests.<sup>50</sup>

In the future, genetic data might be also used to identify not only fathers, but also mothers.<sup>51</sup> It will be an important change especially in those countries where mothers may deliver a child by using a pseudo name. Biological links, of course, had been significant even before using genetic evidence for establishing family links became possible. Family law recognizes this relevance by providing an exclusive right to develop a relationship with the child. It follows from the *de jure* elimination of the discrimination between the children born within and out of the wedlock that legitimization of paternity *post nuptias*, and legitimization based on recognition, is universally accepted in Europe. Moreover, legal systems generally provide equal rights for children born within and outside wedlock.<sup>52</sup>

Lawyers often ask now whether Article 8 of the European Convention on Human Rights<sup>53</sup> (right to respect for private and family life) is applicable to the offspring of donors, saying that it, now brought into UK law by the Human Rights Act of 1998, guarantees the right to form a personal identity. They are also asking whether Article 14 (prohibition of discrimination) can be used to argue that the donor's children should have the same rights as adopted children to trace their genetic parents.

Natural science's ability to provide proof of origin has developed enormously over the past decades as a result of the possibilities provided by genetics.<sup>54</sup> The worldwide demand for the establishment of paternity through genetic testing is expected to

50. The possibility that two unrelated people possess the same DNA band pattern has been calculated to be, on average, 30 billion to one.

51. The practice to keep the mother's identity in secret has a long history, the idea behind this solution might be to avoid infanticide and the shame that a single mother might face.

52. In 1979, the European Human Rights Court recognized both the violation of privacy and discrimination on the ground of birth status in the *Marckx v. Belgium* case (ECHR Case No. 6833/74, Judgement dated June 13, 1979). Published in Series A, vol. 31 (1979–80, 2 EHCR 330), available at [http://www.pravnadatoteka.hr/pdf/aktualno/eng/20021104/Marckx\\_v\\_Belgium.pdf](http://www.pravnadatoteka.hr/pdf/aktualno/eng/20021104/Marckx_v_Belgium.pdf).

53. Convention for the Protection of Human Rights and Fundamental Freedoms (ETS No. 5). Signed in Rome, November 4, 1950. For the official text, as amended in 1994 by Protocol No. 11 (ETS No. 155), see <http://conventions.coe.int/treaty/en/treaties/html/005.htm>.

54. While in the fifties in Hungary, blood tests could at most determine who was *not* the father of a given child in 10–13 percent of the cases, today through blood serum testing and DNA exams paternity can be established with a fair degree of certainty.

grow worldwide, even in cases where no family dispute has arisen.<sup>55</sup> The possibility of finding proof of ancestry, even posthumous proof, and the chance to discover family relations have recently increased significantly. This is in itself perfectly reasonable, but if genetic family relations are overemphasized, this could potentially lead to a dangerous devaluation of non-biological familial ties. The demand for genetic testing of origin is now so irresistible, that at times it takes precedence over respect for the memory of the deceased. Genetic determination of paternity can take place well after death, even after burial.<sup>56</sup>

The social bonds of love, care, and acceptance, as well as the father's declaration of paternity or adoption, are traditionally important aspects of family membership. This is why up until very recently biological proof of family relations has been employed only in exceptional cases. Several years ago, however, biological ancestry became so important that many adopted children also now want to know their 'real' origins. The United Nations' Convention on the Rights of the Child<sup>57</sup> recognizes the child's right to know his or her identity. This right, however, can conflict with other rights of the individual, such as the right to privacy, and with family integrity. So far, in only a very few cases have people attempted to find who their genetic relatives were. DNA identification, however, provides such solid proof that the temptation to uncover family secrets has become great. It appears that in contrast to other approaches, this method of testing has gained validity. The problem increasingly arises in the case of embryos created using donor cells, where the demand to become acquainted with biological identity can arise in adulthood.

In the jurisprudence of the American courts, there are already numerous examples that demonstrate the wide array of legal problems of how genetically determined medical information can be used by family members for medical-preventive purposes. Disclosing the result of the individual genetic test, for example, may spare relatives the harm that may result from continued risk and uncertainty. The court in these cases usually faces the problem of the duty to disclose information to the relatives of a patient who may have some degree of genetic risk. In the *Safer v. Pack*<sup>58</sup> case, the appellants, a patient and husband, contended that *multiple polyposis*, a con-

55. The Swiss Federal Constitution provides everyone the right to have access to information about their ancestors.

56. One well-known case was the post-mortem genetic examination of Yves Montand, ordered by a French court in order to come to a decision in a paternity case.

57. Convention on the Rights of the Child. Adopted and Opened for Signature, Ratification, and Accession by UN General Assembly Resolution 44/25 of 20 November 1989. For the official text, see <http://www.unicef.org/crc/fulltext.htm>.

58. *Safer v. Pack*, Superior Court of New Jersey, Appellate Division (1996) 291 NJ Super 619.

dition which the appellant patient suffered from, was a hereditary condition that, if undiscovered and untreated, invariably led to metastatic colorectal cancer. The appellant patient's father had also suffered from this condition. The appellant contended that the physician who was treating the appellant patient's father knew the hereditary nature of the disease at the time. She also contended that the physician was required, by medical standards then prevailing, to warn those at risk so that they might have the benefits of early examination, monitoring, detection, and treatment, that would provide opportunity to avoid the most baneful consequences of the condition. The court agreed with the appellant. The court held that a physician had a duty to warn those known to be at risk of avoidable harm from a genetically transmissible condition. The court held that there was no essential difference between the type of genetic threat at issue here and the menace of infection, contagion, or a threat of physical harm. Accordingly, the court reversed the order of the trial court, which had previously dismissed the complaint.

In the course of adoption, the adoptive parents might wish to receive proof through genetic 'testing' that they are adopting a healthy child. I believe this is objectionable, and is in contradiction with the policy goals of adoption. The goal of adoption, according to the law, is to establish a familial relationship between the adopters and the adopted. The primary objective of this legal institution is to provide children with a family environment, especially children whose parents are either no longer living, or who are incapable of raising them.<sup>59</sup>

In the first major, already cited report of the UK Human Genetics Commission, it has been estimated that one in ten paternity tests are carried out on children covertly, that is without the consent or knowledge of one of the parents (usually the mother). While the standard practice is to carry out tests on a blood sample or mouth swab, results can be obtained from a single strand of hair or even by analyzing saliva on a used coffee cup. The HGC called for measures to prevent employers and insurers using genetic information from discriminating against people. It proposed that independent bodies should oversee medical research databases, and called for new legislation to prevent police access to such DNA collections. With these recommendations, the HGC is hoping to balance the need for genetic privacy with the need for continued research into the effect of our genes on our health. If scientists are to identify the genes involved in common illnesses such as heart disease, then they will need to examine DNA samples from large numbers of people. The safeguards suggested by the HGC should ensure that such knowledge benefits everyone's health without compromising the privacy of those involved in such studies.

59. Family Law, Section 46.

## 7. Commercial Uses of Genetic Information

### 7.1 Insurance<sup>60</sup>

The biomedical field in the genomic era is predominantly governed by ‘human rights spirited’ health law. One need not be a rights-skeptic to notice that the norms in the medical sector will not automatically influence the norms in the non-medical sector. On the contrary, parallel to the development of important international and domestic legal sources, a gap has gradually opened between the human rights approach and the commercial laws. As a consequence of these trends, a question has to be raised: to what extent principles of medical law apply to related non-medical areas, such as insurance?

The problems of private insurance cannot be explained easily with traditional human rights concepts. In much of Europe, health services rely on general health insurance based on citizenship rights. This is why the measurement of genetic risk is of little significance at present, for it will not lead to higher insurance rates or exclusion from insurance. In the case of life, accident, and disability insurance the situation is markedly different. Here the broad legal principle of *uberrimae fides* rules. This principle assumes the greatest degree of trust between the contracting parties. This is why the individual to be insured may not keep secret any information that may be of significance in the determination of risk.<sup>61</sup> Therefore, if an individual is in possession of a genetic ‘finding’ that effects the risk incurred by the provider of life insurance, then in theory the individual may not keep the information secret from the insurer.<sup>62</sup>

Cases may also arise in which the genetic test would indicate more favorable insurance payments than those traditionally calculated. If, for instance, the insurer’s questions regarding illnesses that have occurred in the family provide a negative picture, but through genetic testing it can be shown that the person to be insured does not carry the gene responsible for the development of the illness, then he or she might avoid paying high premiums set because of the high risk that would otherwise have been determined.

According to Article 12 of the Convention on Human Rights and Biomedicine, a diagnostic genetic test is to be carried out based on proper genetic consultation, and

60. Interviews with Hungarian insurers helped me better understand their point of view. I would like to give special thanks here to Ildikó Takács, who assisted in preparations for these interviews.

61. Tony McGleenan, Urban Wiesing, and Francois Ewald (1999) *Genetics and Insurance* (Oxford: Bios).

62. Neil A. Doherty and Lisa L. Posey (1998) “On the Value of a Checkup: Adverse Selection, Moral Hazard, and the Value of Information,” *Journal of Risk and Insurance*, 65(2): 189–211.



only for medical or scientific research purposes. Hence, the insurer may not compel the insured to undergo genetic testing. It is true that this has not entirely solved the problem because those few who are already in possession of unfortunate results from genetic tests are in a disadvantageous position in establishing the insurance contract. If we add the norms of data protection to this Article, then we find that from the restriction of data provision to the goal of research, existing data can only be used for other purposes with the express permission of the affected individual.

Another problem arises from the fact that insurers ask their clients a fairly broad spectrum of health-related questions. Although the majority of health data requested is traditional medical information, more and more such information in the future will also be genetic in nature.<sup>63</sup> That is, as we learn more about the genetic underpinnings of certain diseases, the genetic component of such data will also increase.

While the applicable medical information forms differ from insurer to insurer, some insurance companies do expressly ask about congenital diseases. Obviously, the insurer is interested in such data because a judgment of the future state of health is very much part of the insurer's job. Certain insurance companies will only consider such data as a domestic effect, while others will use it as indirect proof of higher health risk. If, for instance, there have been a number of cases of cancer or diabetes in the family, it can affect insurance premiums.

### *7.2 Employers and Genetic Information*

Usually the employer does not have the right to see an employee's genetic data. One of the few exceptions could be that it is required for health reasons. In practice, however, it is not easy to separate genetic data collected for various reasons, including the checking of health conditions. This is not even a simple task in the case of traditional medical information. If, for instance, the employer provides life insurance for a number of employees, the employer can fairly easily come to a conclusion about the health of an individual employee through the behavior of the insurer without gaining access to the employee's health documentation. If, for instance, an insurer does not wish to insure three out of forty employees, or is only willing to do so at a higher premium rate, although not warranted by the employees' age, it would be rather easy to come to the conclusion that these employees have a considerable health

63. We may note here that Hungarian insurers have long been interested in diseases in the family. They ask about how long parents and siblings lived, and about the causes of death. This is, in point of fact, a form of genetic data, for in addition to collecting information on their client, they examine the family's health conditions as well.

risk. This fact alone can indirectly affect the employer's decision-making regarding an employee's future career. According to Claude Michele Poissonnet,<sup>64</sup> the genetic test performed in relation with employment jeopardizes the basic rights of the employees, especially the respect for private life.<sup>65</sup>

In the case of mental illness, because of the added threat of stigmatization, individual research projects should examine whether an exposure of genetic factors might lead to further discrimination. Genetic reductionism is especially dangerous in the genetic examination of mental illness. Thus, if genetic research is made on mental illness, its findings always have to be compared with the perspectives of alternative approaches, in order to make room for alternative explanations of the mental condition. One unique characteristic of research on mental illness is that it is difficult to connect the physical, biochemical, or genetic factors to the more complex socially and culturally specific aspects of the determination of psychological illness.

Without an exploration of the connection between genetic factors and environmental effects, genetic information can appear to provide the final word on a condition. This could lead to the conclusion that research results should not be disclosed to relatives. The issue, however, is not so simple. There are cases when a relative may have a legally supportable claim to information that also says something about him or her.<sup>66</sup>

### 7.3 Intellectual Property Rights

After a long and difficult gestation, the European Directive on the legal protection of biotechnological inventions was delivered (Directive 98/44/EC<sup>67</sup>). It is far from easy to analyze its underlying principle. The problem here primarily arises from the fact that in the first paragraph of Article 5,<sup>68</sup> the document finds the mapping of the human body and its constituent parts unworthy of intellectual property right

64. Claude Michele Poissonnet (2003) *Le dépistage génétique en milieu de travail* (Paris: L'Harmattan).

65. In France in 2002, a Parliamentary Act was passed in order to ban such type of genetic discrimination. See Article 4 of *Loi No. 2002-303 du 4 mars 2002 relative aux droits des malades*.

66. According to Hungarian law, for example, relatives cannot be banned from receiving health information also affecting them.

67. Directive 98/44/EC of the European Parliament and the Council of 6 July 1998 on the Legal Protection of Biotechnological Inventions, *Official Journal of the European Communities*, L 213, 30.07.1998, p.13–21. See the Appendix for the official text.

68. Article 5(1): "The human body, at various stages of its formation and development, and the simple discovery of one of its elements, including the sequence or partial sequence of a gene, cannot constitute patentable inventions."

protection. The second paragraph<sup>69</sup> states, however, that the technology that makes it possible to extract these constituent parts, such as genes or gene lines, even to the degree of sequencing, is worthy of protection. The morality of patenting human gene sequences was already examined in 1995 in the *Relaxin* case.<sup>70</sup>

The debate surrounding the Directive is well illustrated by the fact that not long ago the Netherlands attempted, before the European Court in Luxembourg, to eliminate the Directive on biotechnological inventions. The Netherlands argued that plants, animals, or human genetic matter should not be patentable. Italy and Norway supported the Dutch initiative. The Dutch party argued that the right to the integrity of the human body is violated if inventions created using human biological material can enjoy intellectual property right protection, and further that the Directive is also in violation of the principle of subsidiarity. The Dutch here argued that the Directive is not clear, and contradicts itself. These arguments did not impress the court in Luxembourg, and the Directive remains in force.<sup>71</sup> The Court found that the expressions the Netherlands found fault with, such as *ordre public* (public order), to be satisfactorily clear in the Directive.

Article One of the UNESCO Declaration on the Human Genome and Human Rights states that the human genome symbolically represents the “common heritage of humanity.” However, the UNESCO Declaration itself contains a small loophole through which research can escape. According to Article 15, “States should take appropriate steps to provide the framework for the free exercise of research on the human genome with due regard for the principles set out in this Declaration, in order to safeguard respect for human rights, fundamental freedoms and human dignity and to protect public health. They should seek to ensure that research results are not used for non-peaceful purposes.”

It appeared that a UNESCO meeting held in Paris in September, 2001 might result in a new turn in the patenting of the human genome and human genes. The International Bioethics Committee of UNESCO then considered taking up the matter with the World Trade Organization. It intends to insure that Article 27 of the so-called TRIPs (Trade Related Aspects of Intellectual Property Rights) agreement would clearly state that: “the human genome is not patentable on the basis of the

69. Article 5(2): “An element isolated from the human body or otherwise produced by means of technical process, including the sequence of a gene, may constitute a patentable invention, even if the structure of that element is identical to that of a natural element.”

70. *Relaxin* case (1995) *Official Journal of the European Patent Office*, 6: 388.

71. *The Netherlands v. Parliament and Council*, Case No. C-377/98 at the European Court of Justice. See <http://www.curia.eu.int/en/actu/communiqués/cp01/aff/cp0148en.htm> for the press release on the judgment of October 9, 2001.

public interest considerations set out therein, in particular, public order, morality and the protection of human life and health.”<sup>72</sup>

## 8. On the Composition of the Book

### 8.1 *Genetic Information and Biomedical Science*

The first part of the book includes an analysis of the impact of Human Genome Project by two prominent scientists from Hungary. *Pál Venetianer* looks at the major steps in describing and understanding the human genome and demonstrates its relevance in the future of health care. He regards the present development in the field of genetics as a scientific revolution, however, based on different criteria than the one Kuhn applies. The author argues that DNA sequencing, cloning from somatic cells, stem cell technology, and DNA-array (as well as RNA- and protein-array) technology is based on an evolution of technological and methodological innovation and not on a revolutionary change of scientific paradigm.

*István Raskó* examines the use and application of genetic knowledge in various fields of life, predominantly in the field of medicine. However, the author’s analysis goes far beyond the idealized vision of genetics, as he openly discloses fallacies, mis-beliefs, and even uncertainties that exist in biomedical science and in the application of genetic knowledge. He admits that it is not at all evident how to interpret the pool of genetic data. For instance, the spectrum of gene mutations show a population-dependent distribution, that is, patients, say, in the United Kingdom may have gene mutations different from that in Hungary. Therefore tests useful in one population could be useless in another. Besides the biomedical domain, *István Raskó* also explores other fields where genetic information might have important uses, such as forensic medicine, criminology, and genetic archeology. Finally, he explores the problem of how genetic knowledge is communicated to the public and the scientists’ role in this communication.

### 8.2 *Genetic Information: Ethical and Cultural Aspects*

The general public is usually excited about new scientific results, but often becomes critical about the ways genetic information is used and utilized. Scientific discoveries in genetics, and their applications in particular, thus have many policy-

72. Proceedings of the International Bioethics Committee of UNESCO (IBC), 8th Session. (September 14, 2001).

related implications. In order to develop a policy or a protocol on the use of genetic data, at first scrupulous research has to be conducted on the social and ethical impacts of collecting and analyzing genetic information on the individual and the society. The lay public may understand the notions of embryo and stem cell and the individual's own relation to his or her genetic make-up differently from the way scientists do. It is often the case that scientific discoveries are confronted only with the position of the Church, while ethical, sociological, anthropological, legal, and even theological aspects are not heard.

Today two important therapeutic uses of biotechnology, the stem cell-based therapies and the gene transfer techniques, stir the most lively ethical debates. In the *Sixth Framework Program* of the European Commission, preventive and therapeutic tools are regarded as priorities. Nevertheless, because of the ethical concerns of using human embryonic stem cells, funding has been suspended in these contested areas. Stem cells are especially useful for research and therapeutic purposes because they are non-differentiated, they can divide and multiply for a long period and, under certain physiological or experimental conditions, they can also give rise to more specialized differentiated cells.<sup>73</sup> Special ethical problems appear in the autologous collection and transplantation of haematopoietic stem cells.<sup>74</sup>

In the second part of the book, *Imre Szebik* examines the moral dilemmas related to various gene transfer techniques and compares the somatic and germ-line gene transfer techniques. Germ-cell gene transfer techniques are unique in the sense that their effect is not restricted to the patient treated but may affect many generations. This is why many ethicists argue that the use of germ-line gene transfer techniques should be prohibited as future generations may not be able to consent to this intervention. Further ethical problems might arise from the use of the so-called *mitochondrial DNA* (mtDNA) procedures in medically assisted procreation. As a result of the intervention, the offspring will harbor genetic substance from three persons: from her mother, father, and the woman who donated her enucleated egg cell.

In public debates, references to various religious thoughts often play an important role. However, the interpretation of our newly acquired genetic knowledge within the conceptual framework of the existing religious traditions is often very difficult. *Béla*

73. European Commission (2003) *Commission Staff Working Paper: Report on Human Embryonic Stem Cell Research*, SEC(2003)441, 3 April 2003 (Brussels: Commission of the European Communities). Available at [http://europa.eu.int/comm/research/conferences/2003/bioethics/pdf/sec2003-441report\\_en.pdf](http://europa.eu.int/comm/research/conferences/2003/bioethics/pdf/sec2003-441report_en.pdf).

74. Avis No. 74. of the French Consultative National Ethics Committee (Comité consultatif national d'éthique pour les sciences de la vie et de la santé) Les banques de sang de cordon ombilical en vue d'une utilisation autologue ou en recherche.

*Somfai's* chapter provides the reader with a unique analysis of religious thought on stem cell research. He explores the differences and similarities between the Buddhist and Hindu, Islamic and Jewish, Roman Catholic, Protestant, and Eastern Orthodox perspectives. The author also explains the Japanese practice of *mizuko kuyo* (practice that gives respect to the aborted fetus), which does not have a direct theological foundation, but nevertheless evokes various religious ideas. Although it is not easy to find a common position among the different religious traditions, it might be stated that most religions presume the idea of universal humanity: regardless of genetic differences, all members of humanity have common characteristics, and these common elements define our human identity.

### 8.3 Law in the Genetic Era

The advent of the genetic era has given rise to significant legal dilemmas. Among them we can mention such questions as who may own genetic data and information; in what circumstances can a genetic test be performed on children; how can genetic-based discrimination be avoided; and to what extent and in what ways can we protect genetic data. In the third part of the book, these legal questions are discussed in the context of both international legal standards and some national laws.

In the first contribution, *Roberto Andorno* looks at the UNESCO Declaration on the Human Genome and Human Rights, and first describes the circumstances in which the Declaration was formed. After providing the reader with this important historical background, the author then presents and analyzes the basic concepts and main propositions of the UNESCO Declaration: the human genome as a common heritage of humanity; human dignity; informed consent and the right not to know; confidentiality; prohibition of reproductive cloning; germ-line interventions; solidarity; and role of the Member States.

In the next chapter, *David Townend* explores some possible answers to the legal theoretical question: who owns genetic information? Genetic information is used by the individual, by the doctor, by the insurance company, and undoubtedly it has some commercial value. Given this wide range of affected individuals, groups of individuals, and institutions, it is not evident what legal concept best protects this information. The traditional route for protection of genetic information is privacy. This involves the control of information and the respect afforded to this information. Genetic information, however, is made subject also to property rights through patents where control over information is regulated differently than in case of personal genetic data.

In the third essay of this section, *Sheila McLean* analyzes the legal problems of conducting genetic testing on children. The author emphasizes that genetic tests are

special among medical tests in that the link between diagnosis and therapy here is uncertain and therefore when the child is unable to consent to testing, it is very unlikely that testing serves the interest of the individual child directly. Genetic conditions have life-long consequences and therefore decisions made on behalf of the child may influence many important aspects of the child's future. Thus, the main questions that legal scholars and policy-makers have to face is: who and in what circumstances has the authority to make decisions on the child's genetic testing?

In the next chapter, *Gregor Wolbring* proposes a disability rights approach to the formulation of laws prohibiting genetic discrimination. The main thrust in the author's argument is that the prevailing discourse of disability treats disabled people as a medical problem, which can be solved only by some form of medical or technological intervention. This view in itself is discriminatory because it distinguishes between various biomedical and genetic conditions, implicitly selecting between 'good' and 'bad' traits. The author recommends the replacement of this medical model of disability with a social justice model of disability, which puts the issue of disability discrimination in a human rights perspective. The current focus on 'fixing' disability up to a certain norm gets an ironic twist in the third, 'transhumanist' model of disability, which emphasizes that the emerging genetic and non-genetic enhancement techniques might make what is presently seen as 'subnormal' actually 'supranormal' in the future.

In the last contribution to this section of the volume, *Jürgen Simon* provides an important contribution to the contemporary legal discussions of how much and what kind of genetic information insurance companies may use. In Germany, the Insurance Contract Act stipulates that the insurance applicant is obliged to give all information he has about the state of his health that is relevant for the insurance contract and the insurer. Obligation means that its defiance could exclude the insurance benefits. According to the Insurance Contract Act, all circumstances are relevant that the insurer has expressly and in a written form asked for. Apart from the analysis of the German law, Simon also offers a comparison between the different national legal models of how the insurance business treats genetic test results.

#### 8.4 Genetic Databanks

The fourth part of the book deals with different models of national genome projects and biobanks. Scientists, pharmaceutical companies, public health experts, insurance companies, as well as the society in general, are all interested in the collection and classification of genetic data in large databases and in the biomedical and genetic research that is based on them. Tissues, blood samples, and other biological material obtained in medical and therapeutic institutions may be rich sources of

genetic information. Biotechnological companies that aim to uncover the relationships between specific genetic sequences and particular diseases, might be particularly interested in the commercialization of genetic information. The donors of biological material, thus of genetic information, however, should be able to give a second consent if these data are used for research purposes beyond the therapeutic sector.

The establishment and operation of national genetic databanks and other institutionalized genome projects, whether they are used solely to store genetic data, to process such data, or to operate as a tissue bank, require special regulation. Further and more problematic legal issues may arise if a genetic databank is used to conduct research on mental illness or to explore the genetic background of human behavior.

The first national law in this specific field is the Act No. 139 of 1998 on a Health Sector Database of Iceland.<sup>75</sup> *Ragnar Aðalsteinsson* provides a history of the Icelandic genome project and analyzes the legal and social concerns of the first population-based gene collection enterprise. It is well known that relatively homogeneous communities are especially interesting resources for genetic research. This was recognized in 1996 by Dr. Kari Stefansson who established the company deCode Genetics, Inc. in order to finance genetic research in Iceland. The company asked for and received an exclusive license to build a database from the medical records of the Icelandic population. According to opinion surveys, the population of Iceland originally supported the idea to provide a 12-year exclusive license to deCode. The Health Sector Database Act, however, introduced an opting-out model (which presumed the consent of the donors) instead of an opting-in model (which would have required the explicit, informed consent of the donors). The support for the large-scale data collection was taken for granted and any individual who did not want to participate had to express refusal. In 2001 another Act was passed which allowed the use of the collected biological samples for the purposes of clinical tests or treatment.

The Estonian Genome Project is presented by *Krista Kruuv*, the executive director of the project and *Ants Nõmper*, a lawyer who actively participated in working out the legal issues of the project. Besides providing a useful comparison of the Estonian project with the Icelandic database, the contribution also analyzes the Estonian Human Genes Research Act.<sup>76</sup> Under this Act, every gene donor has the right to remain anonymous after coding; to permit disclosure of his or her identity; to disclose the fact of being or not being a gene donor and the circumstances thereof, unless otherwise prescribed by law; not to know their genetic data; to access their data for free except genealogies stored in the Gene Bank; and to receive genetic counseling upon accessing their data.

75. For the official text of the Health Sector Database Act of Iceland, see Appendix to this volume.

76. For the official text of the Human Genes Research Act of Estonia, see Appendix to this volume.



In the Latvian Human Genome Research Act<sup>77</sup>, gene donors' rights are based on the informed consent procedure. This is an agreement to provide a tissue sample for the Genome Database, to obtain health description and genealogy, and to use the tissue, health description, and genealogy for genetic research, public health research, and statistical purposes. In this model, all personal data is replaced with a code, which enables the reverse identification of the gene donor, including the name, personal code, and residence. The code shall be indicated on the written informed consent of the gene donor. Under the Latvian law, gene donors have the right to access their data stored in the Genome Database and the right to genetic counseling.

National biobanks and genome projects are usually analyzed in a scientific or legal context, but the social and cultural dimensions of these projects are very rarely explored. However, it is particularly important to discuss these issues, as population-based genetic research constructs group identities. *Aivita Putniņa* explores a specific example of how national biobanks might take part in constructing cultural identities. The author distinguishes three basic discourses that justify the Latvian Genome Project. The first one is related to the particular socio-historic context of Latvia (political concerns about independence, positioning Latvia on the global map, and nationalism are reflected in the incentives of the genome project). The search for a 'Baltic gene', for example, has a strong political and cultural meaning. The second discourse concerns the strategic placement of biomedical science in the public and political fields. And finally, the third dimension focuses on public health policy aspects.

In the last contribution to this section, *Alan Doyle*, *Frances Rawle*, and *Peter Greenaway* provide an insight into the operation of the UK Biobank. This includes collecting samples and analyzing multifactorial diseases of adult life in 500,000 volunteers aged 45–69 selected at random from the UK population. From this study, important personal information, such as lifestyle information, may be derived. The UK data collection includes follow-up by tracking through healthcare records over an extended period including the use of existing disease registers. In the UK Biobank, both the database and the biological samples will be made accessible to the academic and commercial research communities under a carefully planned ethical and legal framework on an anonymized basis. As volunteers will be recruited on an entirely opt-in basis (the consent has to be explicit), there has been and will continue to be considerable open debate and consultation on all of the issues surrounding the project.

77. The Human Genome Research Act came into force on January 1, 2003, and was amended in June, 2003. With the amendments, the Act will finally enter into force on January 1, 2004. For the official text of the Act as well as its amendment, see the Appendix to this volume.

Those countries where the questions of genetic discrimination and data protection have not yet been discussed in front of the broad public, could very easily become 'genetic resource countries' for other countries that conduct advanced genetic research. Therefore it is of utmost importance that legal and ethical issues of genetics are discussed in a comparative context.

## 9. Closing Thoughts

In the future genetic information will become increasingly important to society, for it can enhance our understanding of the appearance and development of disease and can increase the effectiveness of treatment. In addition to researchers of the biomedical field, social scientists will also eagerly use this information for their research. Of course, serious economic interests also underlie curiosity on genetics. Employers and insurers have an interest in using the genetic data of their employees, clients, and future partners in order to reduce risk, or optimize the use of labor.

We should be aware that as our knowledge of genetics accumulates, we ourselves also become more 'transparent'. Regulations providing for the right to control the body are not up to the task of assisting us in developing rules on the use of human gene samples. It is important to recognize that medical and genetic information may be detached from the human body: even though the body dies, the gene set lives on, thus even a deceased person could be a source of valuable information. Uncovering all the secrets of our genes will still take some time, but it appears that the twenty-first century will present us with an ever more precise picture of our genes.

Our knowledge of human genetics will doubtless provide us with a great many advantages, but if we deprive our individuality of every non-genetic attribute and separate it from its human and cultural connections, science could fall into the trap of genetic reductionism. As in the case of every new scientific paradigm, if scientists and laypeople alike take the genetic 'code' out of the social context they can give rise to unforeseen and unwelcome consequences.

The genomic era provides us with a vast range of biomedical and socio-cultural benefits. But in order to enjoy these benefits, it is necessary to spread education across the disciplines, and to allow for negotiation and mutual interpretation between them. I believe that this multidisciplinary book on society and genetic information will be a valuable contribution to various scientific and political discussions, and it will be of interest to lawyers, policy makers, philosophers, and social scientists as well.

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