

Bastian B. Haberland

GERM-LINE INTERVENTIONS IN THE INTERNATIONAL
REGIME OF HUMAN RIGHTS AND HUMAN DIGNITY

GERM-LINE INTERVENTIONS IN THE INTERNATIONAL
REGIME OF HUMAN RIGHTS AND HUMAN DIGNITY

ABSTRACT: *Germ-line interventions allow parents to take influence on their child's genetic disposition and give scientists the means to eradicate hereditary diseases. At the same time, nothing is more controversial in the realm of genetics than the child as an object of parental gustoes - the "designed child". This article begins with an overview of the international regulations dealing with germ-line interventions. It then turns to the question whether there are international human rights that promote a permissive policy towards germ-line interventions, such as the right to health, as opposed to those international rules that seem to restrict the application of germ-line interventions, such as human dignity. The analysis results in the conclusion that the prohibition of germ-line interventions for non-therapeutic purposes is an evolving rule of customary international law. In order to give this rule a more tangible outline, the appendix contains the draft of a "Declaration on the Prohibition of Non-Therapeutic Germ-line Interventions".*

I. INTRODUCTION.....	3
II. GENOMICS IN A NUTSHELL.....	7
The Human Genome.....	7
Human Germ-line Interventions.....	8
III. GENOMICS-SPECIFIC INTERNATIONAL LAW	12
The Genome as an Object of Public International Law.....	13
The 1997 European Convention on Human Rights and Biomedicine.....	14
The 1997 Universal Declaration on the Human Genome and Human Rights.....	16
The 2005 Universal Declaration on Bioethics and Human Rights.....	19
Conclusion.....	21
IV. GENOMICS AND INTERNATIONAL HUMAN RIGHTS LAW	21
Genome Interventions and Permissive International Human Rights Law.....	22
(1) Consent	23
(2) Procreative Liberties.....	24
(3) The Rights of the Child and Future Generations	27
(4) The Right to Health.....	32
(5) The Right to Benefit from Scientific Progress and the Freedom of Scientific Research....	36
(6) Conclusion	38
Genome Interventions and Restrictive International Law	39
(1) Human Dignity.....	39
(2) The Rights of Others and Duties to Society.....	46
(3) The Prohibition of Germ-line Interventions for Non-Therapeutic Purposes – An Evolving Customary Rule	48
(4) Conclusion	51
IV. CONCLUSIONS.....	51
V. APPENDIX	54

¹ Bastian B. Haberland works as a judge at the Magistrate's Court in Kleve, Germany. He is a law graduate of Heinrich-Heine-University Dusseldorf, Germany, and passed his First (2004) and Second (2008) State Exam in Law in Germany. This article is adapted from his dissertation that was submitted in partial fulfilment of the requirements of the degree of Master of Laws (International Law and Politics) at the University of Canterbury in 2006. The author is grateful to Dr Chris Gallavin, University of Canterbury, for his helpful advice during the creation of this paper, and to Dr Neil Boister, University of Canterbury, for being an inspiring lecturer.

I. INTRODUCTION

'I not only think that we will tamper with Mother Nature, I think Mother wants us to.' Writer and director Andrew Niccol chose this statement by Professor Willard Gaylin of Columbia University for the opening sequence of his 1997 motion picture *Gattaca*. Based on Robert Heinlein's 1942 novel *Beyond This Horizon*, Niccol's film pictures a society in which humanity has optimised the utilisation of its genetic potential and nearly eradicated physical and mental dysfunctions. Genetic determinism has marginalized individuals without genetic enhancement and has created a meritocracy based entirely on a person's genetic disposition. Heinlein's dystopia is written in the tradition of Aldous Huxley's 1932 narrative *Brave New World*, in which a carefree, healthy and technologically advanced humanity lives in a strict system of social stratification. Both scenarios correspond to the common fear that humankind will have to buy the prospect of a higher standard of living through genetic engineering in exchange for the abandonment of social diversity and individual liberties. In contrast to this dystopian view, the ability to improve the quality of life, to increase the standard of health and to bring out the best in the human race seems an almost insurmountable temptation. The excitement about genetics, however, is habitually dampened by the unpredictability of the social and biological long-term consequences of an artificially altered human gene pool. Although global effects on the human species will not be detectable until the next millennium the gene pool might experience irreversible and incalculable alterations within only one generation. Then again, the genetically improved human might as well be a type of evolutionary selection that is necessary in the next stage of humankind.² Natural alterations of the gene pool would compete with human interventions that critics label "unnatural". However, the unpredictable evolutionary process of natural selection will still determine human survivability. Evolution is neutral and "minds" neither if we opt for genetic engineering nor if the human species becomes extinct like so many species before.

However, not all methods of genetic engineering have the same profound effects. Somatic cell interventions, for example, aim at curing or preventing genetic diseases but affect the individual organism only. Indirect germ-line interventions make use of genetic information and take influence on reproductive decisions. A well-known example is the rejection of embryos or the decision not to procreate at all if the genetic dispositions in the

² Daniel E. Koshland Jr., 'The Future of Biological Research: What is Possible and What is Ethical?' (1988-89) 3(2) *MBL Science* 11, 12.

parental genes predict severe complications.³ In contrast to those methods, direct germ-line interventions result in an inheritable change of an individual's genetic material by inserting desirable genes or deactivating undesirable genes in germ-line cells.⁴ The specific feature of transferring genetic alterations to possible offspring makes the method both interesting and risky. It is interesting because it can prevent inherited diseases and patch genetic defects. It is risky because the biological consequences are uncertain and parents and social influences could impose their gustoes on the unborn child.

The social implications of germ-line interventions are obvious. Moral, ethical and biological uneasiness is prone to be sidelined by the temptation of a better, a close-to-perfect life and the elusiveness of the supposed risks for future generations. Some techniques may be desired by the majority of individuals but at the same time cause wider public concern. An often-cited example is the “designed child” and its potential to aggravate discriminatory behaviour against people who do not meet the socially determined genetic standard. To an unprecedented degree, individual choices would have serious impact on humanity's self-conception and biological design. While hitherto scientific interventions mostly affected individuals as subjects, genetic engineering could make individuals objects of a higher cause. This “higher cause”, however, is very susceptible to abusive interpretations and seems impossible to determine universally since ethical boundaries vary between individuals, families, nations and cultures. For this reason, a global response to germ-line interventions would have to overcome a lot of social as well as legal difficulties and ambiguities. A genetically improved genetic human standard, for example, would challenge the various non-discrimination clauses throughout the body of human rights law.⁵ Moreover, States might have to restrict access to genetic engineering to prevent individuals and private biotechnology firms from jeopardising the genetic diversity of humankind. They would be advocates for genetic diversity and for the inviolability of the gene pool of future generations. As advocates, they could underpin their argument by referring to the right of future generations to be free of genetic alterations made without their consent,⁶ a child's right to an untouched genetic

³ Alan Buchanan, Dan W. Brock, Norman Daniels and Daniel Wikler, *From Chance to Choice – Genetics and Justice* (2000) 6-7.

⁴ Desmond S.T. Nicholl, *An Introduction to Genetic Engineering* (2nd ed, 2002) 210-1.

⁵ Iulia-Antoanella Motoc, *Specific Human Rights Issues: Human Rights and Bioethics*, United Nations Economic and Social Council, Commission on Human Rights, Sub-Commission on the Promotion and Protection of Human Rights, 55th sess, [39-44], UN Doc E/CN.4/Sub.2/2003/36 (2003).

⁶ Margaret Somerville, ‘Introduction to Section V(d): Reproduction, Technologies and Human Rights’ in Kathleen E. Mahoney and Paul Mahoney (eds) *Human Rights in the Twenty-first Century: A Global Challenge* (1993) 873.

inheritance⁷ or the collective human right to live in a genetically diverse world.⁸ In order to protect the human genome States could also bring up the Common Heritage of Humankind principle.⁹ Conversely, individuals could claim that it is their legitimate right to interfere with their genome as they please. They could rely on the States' human rights obligations that seek to limit the interference with an individual's personal and corporal integrity and guarantee access to social and economic resources.¹⁰ Indeed, individuals could raise some human rights whose language seem to support the development and use of germ-line interventions¹¹ such as the freedom of reproduction, the protection of the family, the rights of the child and the right to the highest attainable standard of health. Then again, all those rights contained in binding and non-binding norms and declarations cover genomics very generally (if at all) and the derivation of genetic rights could go beyond their traditional interpretations.¹² Even though radical interpretations seem possible, are they advisable? Individual freedoms always need to be linked with their societal impacts, which is especially relevant in the realm of genetics where the exercise of far-reaching genetic rights might have detrimental effects on humankind as a whole. To avoid such developments, States could be entitled to limit those rights and secure 'due recognition and respect for the rights and freedoms of others.'¹³

This short overview on the controversies concerning germ-line interventions also serves as an outline for this article. The juxtaposition of the pros and cons of germ-line interventions and the Janus-faced nature of most arguments will serve as another leitmotiv. In chapter III, I will go further into the question of whether there are rights that favour germ-line interventions. I will answer this question in the affirmative only for the right to benefit from scientific progress and the freedom of research. Every other right that could be invoked has not yet reached a level of recognition where they would contain a "right to germ-line interventions". The most important factor in this context is that the general concept of "rights of future generations" has not yet gained a foothold in international law. After this first part of

⁷ W. French Anderson, 'Human Gene Therapy' in Tom L. Beauchamp and LeRoy Walters (eds) *Contemporary Issues in Bioethics* (4th ed, 1994) 665.

⁸ Maha F. Munayyer, 'Genetic Testing and Germ-Line Manipulation: Constructing a New Language for International Human Rights' (1997) 12 *American University Journal of International Law and Policy* 687, 717.

⁹ J.M. Spector, 'The Fruit of the Human Genome Tree: Cautionary Tales About Technology, Investment, and the Heritage of Humankind' (2001) 23 *Loyola of Los Angeles International & Comparative Law Review* 1; Melissa L. Sturges, 'Who Should Hold Property Rights to the Human Genome? An Application of the Common Heritage of Humankind' (1997) 13 *American University International Law Review* 219.

¹⁰ Alastair T. Iles, 'The Human Genome Project: A Challenge to the Human Rights Framework' (1996) 9 *Harvard Human Rights Journal* 27, 28.

¹¹ Stephen P. Marks, 'Tying Prometheus Down: The International Law of Human Genetic Manipulation' (2002) 3 *Chicago Journal of International Law* 115, 122; see especially Munayyer, above n 8, 701.

¹² Iles, above n 10, 36.

¹³ See e.g. the *Universal Declaration of Human Rights* or *International Bill of Human Rights*, GA Res 217 (III), UN GAOR, 3rd sess, 183rd plen mtg, UN Doc A/RES/217(III) art 29(2) (1948) ('*Universal Declaration of Human Rights*').

the analysis, I will elaborate whether the right to benefit from scientific progress and the freedom of research are limited by other rights that restrict interventions into the human germ-line. I will show that, despite its frequent appearance in the discussion on genetics, the concept of human dignity does not necessarily exclude germ-line interventions. Besides that, all other supposedly restrictive rights suffer from the same lack of recognition of the concept of rights of future generations as their permissive counterparts. Nevertheless, my study will reveal that there is unanimous international opposition to interventions for non-therapeutic purposes, which has the potential to develop into a rule of customary international law. So far, this opposition is only expressed in international documents set up by the United Nations Educational, Scientific and Cultural Organization (UNESCO) and by the Council of Europe, namely the 1997 Universal Declaration on the Human Genome and Human Rights¹⁴ and the 1997 European Convention on Human Rights and Biomedicine.¹⁵ It is their drafting histories and various reports that support the argument for an evolving customary prohibition of germ-line interventions for non-therapeutic purposes. In chapter II, I will discuss in detail how those regulations as well as UNESCO's Universal Declaration on Bioethics and Human Rights of October 2005¹⁶ deal with said ambiguities and the conflict of supposedly permissive and restrictive human rights. Since those texts still form a rather incoherent picture and international consensus is needed I will suggest the drafting of a new declaration that clearly prohibits germ-line interventions for non-therapeutic purposes. It is designed for endorsement by UNESCO's General Conference or the UN General Assembly and could eventually be an initial step toward the preparation and conclusion of a binding convention.¹⁷

Limited space demands several limitations to the scope of this treatise. Firstly, I will only focus on direct germ-line interventions. Indirect interventions prevent the birth of individuals with unwanted traits, whereas direct interventions immediately interfere with a future person's genetic material, which poses different legal and ethical questions. Hence, whenever the term "germ-line intervention" is used hereinafter it describes direct germ-line interventions. Secondly, the legal issues of the patentability of genes and the overall legality of genome interventions are only partly congruent. Even proponents of patent protection for

¹⁴ *Universal Declaration on the Human Genome and Human Rights*, adopted by the General Conference of UNESCO at its 29th session, 11 Nov 1997, UN Doc ST/HR/1/Rev.6(Vol.I/Part1) 459-464 (2002).

¹⁵ *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*, opened for signature 4 April 1997, ETS No 164 (entered into force 1 December 1999) ('*Convention on Human Rights and Biomedicine*').

¹⁶ *Universal Declaration on Bioethics and Human Rights*, adopted by acclamation on 19 October 2005, General Conference of UNESCO, 33rd sess, UNESCO < http://portal.unesco.org/shs/en/ev.phpRL_ID=1883&URL_DO=DO_TOPIC&URL_SECTION=201.html > at 21 October 2007 ('*Universal Declaration on Bioethics and Human Rights*').

¹⁷ See also Noëlle Lenoir, 'Universal Declaration on the Human Genome and Human Rights: The First Legal and Ethical Framework at the Global Level' (1998-1999) 30 *Columbia Human Rights Law Review* 537, 549-550.

human genes stress that patents would not allow the patent-holders to interfere with the gene as they please.¹⁸ For this reason, I will not address the human right to the protection of intellectual property¹⁹ and aspects of world trade law. Thirdly, feasible medical procedures are still a distant prospect and experiments on humans will be inevitable to make the application of germ-line interventions safe. Those procedures will pose challenges to the human rights framework themselves but cannot be addressed here. Finally, this article merely examines the interrelations of human rights between individuals – born and yet unborn. In this context, States act as mediators entitled to balance those rights rather than mere executors of state authority.²⁰ That is not to say that there is no danger of coercive governmental policies in the sense of enforced genetic treatment.²¹ Needless to say that those and other important ethical and moral questions on eugenics further complicate the legal situation and require more attention than I can pay here.

The notion of eugenics casts its shadow in large parts because of the hideous ways in which eugenic practices were pursued in the first half of the 20th century, particularly in Nazi Germany.²² Nowadays, the endeavour to make the benefits of germ-line interventions accessible and at the same time avoid hazardous and abusive developments determines the discussion. As I will show later, this is the case in both the philosophical and the legal world. Since the notions of genetic engineering and eugenics still are a red rag to many people, it is essential to know what germ-line interventions are and what they can do. Hence, I will use the following chapter for a short introduction to genomics. For the sake of a better understanding the descriptions are simplified and limited to the aspects relevant for our topic.

II. GENOMICS IN A NUTSHELL

The Human Genome

As far as scientists know today every living organism possesses a genome containing the biological information needed for the construction and maintenance of a living example of that organism.²³ Apart from a few viruses, all genomes are made of deoxyribonucleic acid (DNA). DNA is a substantially long molecule made up of chains of nucleotides, which consist

¹⁸ Shira Pridan-Frank 'Human Genomics: A Challenge to the Rules of the Game of International Law' (2002) 40 *Columbia Journal of Transnational Law* 619, 630.

¹⁹ *Universal Declaration on the Human Genome and Human Rights*, above n 14, art 27(2).

²⁰ Munayyer, above n 8, 690.

²¹ For example, China's Law on Maternal and Infant Health of 1995, though supposedly not motivated by racism but by a desire to reduce birth defects, imposes decisions on couples for eugenic reasons. See Qiu Renzong, *Is Chinas Law Eugenic? - 'A Concern for Collective Good'* and the critical response by Frank Dikötter, *Is Chinas Law Eugenic? - 'The Legislation Imposes Decisions'* (1999) UNESCO Courier <http://www.unesco.org/courier/1999_09/uk/dossier/txt07.htm> at 21 October 2007.

²² Buchanan et al, above n 3, 60.

²³ See generally T.A. Brown, *Genomes* (1999).

of a sugar and a phosphate group and one of the four bases adenine, cytosine, guanine and thymine. Two strands of DNA create the well-known double helix structure, held together by hydrogen bonds between the bases, which group in pairs of adenine and thymine or guanine and cytosine. Genes are distinct sequences on the double helix that contain the information that is essential for the construction and regulation of specific molecules that function as the organism's construction and maintenance crew. Every human nuclear genome contains approximately 30,000 genes,²⁴ which can be associated with certain functions or traits of the individual organism. The specific composition of an individual gene might determine, for example, if a human being has blue or brown eyes. However, in most cases the situation is more complex. Scientists consider it unlikely that variations within a single human gene fully determine the genetic predisposition for a certain trait. They consider the interaction of genes and the interplay between genes and environment to be the norm with regard to traits and also to hereditary diseases.²⁵ Despite these complex interrelations and the controversy on the heritability of behavioural traits, scientists hope that genes can play an important role in the treatment of hereditary diseases and the suppression of "undesirable" characteristics. Since the isolation of single genes and identification of associated traits are time-consuming and expensive, the Human Genome Project (HGP) was established in the late 1980s as a loose but organized collaboration between geneticists worldwide. The task of sequencing 3×10^9 human base pairs was realized on 26 June 2000 when the first draft of the human genome sequence was announced. On 14 April 2003, the International Human Genome Sequencing Consortium declared the successful completion of the project. From then on, the emphasis in research shifted from the question what the genome *is* to the question what it *does*.²⁶ It does not come as a surprise that the second question proved to be even more complicated than the first.

Human Germ-line Interventions

The term "human genome" describes the genomes of many different individuals and the collected knowledge of their genetic characteristics. Apart from identical twins, no two individuals in the world have an identical genome. However, one can speak of *the* human genome since differences between individuals are generated from an overall variation of only

²⁴ Roger C. Green, 'Human Genetic Diseases' in Christoph W. Sensen (ed) *Handbook of Genome Research* (2005) vol.1, 81, 81.

²⁵ *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, Explanatory Report* (1996) [79] Council of Europe <<http://conventions.coe.int/Treaty/EN/Reports/Html/164.htm>> at 21 October 2007 ('*Convention on Human Rights and Biomedicine, Explanatory Report*').

²⁶ Brown, *ibid* 388; Nicholl, *above n* 4, 175.

0.1 per cent.²⁷ An individual genome emerges from the process of human reproduction when mother and father randomly donate half of their DNA to the sex cells. These cells then, through a variety of processes, shuffle the genes into new combinations and eventually form the offspring's genome. The genome is organized in 46 chromosomes, made up of 23 pairs, one member of each pair contributed by the mother, the other by the father. Hence, every gene exists in two copies but only one copy is expressed as a trait. The advantage of sexual reproduction as opposed to asexual reproduction is the large amount of variation in the offspring's genes that makes the organism less susceptible to diseases. The downside of sexual reproduction is that the offspring also inherits genes that might be implicated in the causation of diseases. To identify and disarm those genes is the purpose of gene therapy. The alteration of genes is based on the premise that genetic information is a resource that can be manipulated to achieve certain goals in science and medicine.²⁸

In a geneticist's toolbox, we find instruments for the manipulation, cloning, screening and modification of genes. Germ-line interventions are realised by altering the genetic material in the reproductive cells of an adult. While this allows people to reproduce without worrying about the transfer of hereditary diseases to their offspring, complications of the "unnatural" genetic disposition cannot be ruled out. Genetic interventions could have an immediate, unforeseen and harmful effect on the child. They could also lurk in the background and manifest in later generations. The consequences for humankind could be disastrous since scientists have found out that in evolutionary history large-scale germ-line mutations within a species have usually been rather detrimental than beneficial.²⁹ When the basic tools to recombine DNA became available in the 1970s it was already understood that 'the new technology could give rise to potentially harmful organisms, exhibiting undesirable characteristics.'³⁰ At the same time, molecular biologists found it reasonable that

keeping diabetics alive with insulin, which increases the propagation of an inherited disease, seems justified only if one ultimately is willing to do genetic engineering to remove diabetes from the germline and thus save the anguish and cost to millions of diabetics.³¹

²⁷ Nicholl, above n 4, 169.

²⁸ Ibid 3.

²⁹ David Bricker, *A New Hypothesis on the Origin of 'Junk' DNA* (2003) Innovations-Report, Forum for Science, Industry and Business <http://www.innovations-report.com/html/reports/life_sciences/report-23583.html> at 21 October 2007.

³⁰ Nicholl, above n 4, 6.

³¹ Koshland Jr, above n 2, 12.

Supporters of this opinion regard the fears of detrimental consequences for future generations as too speculative to justify denying the benefits of germ-line interventions to more immediate offspring.³² Not only for them, the idea to eradicate at least the prevalent genetic diseases like Down's syndrome (Trisomy-21) or mucoviscidosis (cystic fibrosis) is very tempting. Scientists have already managed to connect numerous hereditary diseases with certain genes.³³ However, in a book on genome research published in 2005, the author Roger Green stated that even where the underlying patho-physiology was known and access to the critical cell was feasible, advances in gene therapy of inherited diseases have been few.³⁴ Altogether, the huge number of genomes and the expected slow dissemination of "healthy specimens" render 'the elimination of "harmful" genes from entire human populations [...] more utopian than realistic.'³⁵ Yet the potential threat is taken so seriously that the Swiss constitution goes so far as to prohibit even the transfer of non-human genetic material into the human genome,³⁶ a procedure even more controversial than germ-line interventions. All this illustrates that the discussion on germ-line interventions is far ahead of scientific progress. Some hope that this condition will prevent harmful developments and favour less controversial alternatives;³⁷ others fear that premature limitations might overlook the benefits of genomics.

But how should we handle "abnormal" genetic constellations that benefit a person. A well-known example is the protection from contracting malaria if a person carries only one copy of the gene for sickle-cell disease.³⁸ The eradication of "abnormal" genes might therefore hinder unforeseen beneficial developments. In addition, some diseased genes could have positive effects on some people's lives and even humankind as a whole. The question arises whether we want to prevent persons with a genetic predisposition for bipolar disorder

³² John A. Robertson, *Children of Choice – Freedom and the New Reproductive Technologies* (1994) 162.

³³ See the more than 16,000 entries in the database *Online Mendelian Inheritance in Man*TM (2000) McKusick-Nathans Institute for Genetic Medicine, Johns Hopkins University, and National Center for Biotechnology Information, National Library of Medicine <<http://www.ncbi.nlm.nih.gov/omim/>> at 21 October 2007.

³⁴ Green, above n 24, 87.

³⁵ Hans Galjaard, *Report of the IBC on Pre-Implantation Diagnosis and Germ-line Intervention*, [82], UNESCO Doc SHS-EST/02/CIB-9/2(Rev.3) (2003).

³⁶ Art.119(2)(b): 'le patrimoine génétique et germinale non humain ne peut être ni transféré dans le patrimoine germinale humaine ni fusionné avec celui-ci' *Constitution fédérale de la Confédération suisse* (2005) Confoederatio Helvetica <<http://www.admin.ch/ch/fr/rs/101/a119.html>> at 21 October 2007.

³⁷ such as somatic cell interventions, donations of genetically "healthy" eggs and sperms, prenatal diagnosis, embryo selection and abortion; see Council for Responsible Genetics, *Human Germline Manipulation* (2000) Council for Responsible Genetics <<http://www.gene-watch.org/programs/cloning/germline-position.html>> at 21 October 2007; Harold Edgar and Thomas Tursz, *Report on Human Gene Therapy*, UNESCO Doc SHS-94/CONF.011/8, 15-6 (1994).

³⁸ *Control of Genetic Diseases*, Report of the Secretariat of the World Health Organization, 21 April 2005, WHO Doc EB116/3 (2005) para 3 ('*Control of Genetic Diseases*').

when this mood disorder has had influence on the work of so many outstanding artists.³⁹ Would theoretical physicist Stephen Hawking's mind have been as brilliant if his parents had decided to switch off the gene that causes motor neurone diseases?⁴⁰ Significantly, his own statements on his defect reveal that the diagnosis gave new impetus to his life and research.⁴¹ For that reason it is not surprising that a working group of UNESCO's International Bioethics Committee (IBC) found in 1994 that it 'would not categorically oppose any and all imaginable intervention on the germ-line.'⁴² In a report of 2002, the World Health Organization concurred with that view.⁴³ Despite this reluctance to generally ban germ-line interventions, most States in the early 90s endorsed their outright prohibition due to the insufficient knowledge to evaluate the risks to future generations.⁴⁴ Still in 2003, the IBC stated that in most nations germ-line interventions had been 'strongly discouraged or legally banned.'⁴⁵

An explanation for this attitude could be the parallelism between genomics and the beginning of the atomic age, the weighing of pros and cons of immense powers that can be used for good and evil. Maybe the international community does not want to make the same mistakes again? As for nuclear powers, humankind – after a long period of arming and mutual deterrence – nowadays seeks to limit the use of atomic energy to peaceful purposes, but even minor accidents in nuclear power plants bear the risk of nuclear contamination and death. In addition, the discussions on the atomic programmes in Iran or North Korea, the back and forth between India and Pakistan, and the mystery-mongering about the Israeli atomic programme reveal that there can be no certainty. Does international law provide promising means to take influence on scientific progress and the control of risky developments? Some scholars argue that it is science and technology that determine or alter the ends, means and structures of international law⁴⁶ and not vice versa. From a positivist's point of view, a more optimistic

³⁹ See generally Kay Redfield Jamison, *Touched with Fire: Manic-Depressive Illness and the Artistic Temperament* (1993).

⁴⁰ I don't know the actual cause of Stephen Hawking's disease. I am also aware of the fact that only 5-10 per cent of cases of motor neurone diseases are identified as genetic/hereditary. See generally MND Association, *Causes of MND* (2005) Motor Neurone Association <http://www.mndassociation.org/research/research_explained/causes/index.html> at 21 October 2007.

⁴¹ Stephen Hawking, *My experience with ALS* (2005) Professor Stephen W. Hawking's web pages <<http://www.hawking.org.uk/disable/dindex.html>> at 21 October 2007.

⁴² Edgar and Tursz, *ibid* 17.

⁴³ World Health Organization (ed) *Genomics and World Health, Report of the Advisory Committee on Health Research* (2002) 113 ('*WHO-Report*').

⁴⁴ Edgar and Tursz, above n 37, 14; see also Tom Wilkie, *Perilous Knowledge* (1993) 158.

⁴⁵ Galjaard, above n 35, para 100.

⁴⁶ Joseph W. Dellapenna, 'Law in a Shrinking World: The Interaction of Science and Technology with International Law' (1999-2000) 88 *Kentucky Law Journal* 809, 881.

standpoint is to say that ‘human must give directions to science’⁴⁷ and that international law could provide the according means. Despite said shortcomings of the Treaty on the Non-proliferation of Nuclear Weapons⁴⁸ I would like to join the chorus of optimists and predict that international law will play an important role in the history of germ-line interventions. The spirits, the natural powers that could ignore our commands, have not been cited yet.⁴⁹ In contrast to the Treaty on the Non-proliferation of Nuclear Weapons, this time the international community has the chance to take influence on scientific progress before it is happening. As a starting point, I will use the following chapter to present current international regulations dealing with germ-line interventions.

III. GENOMICS-SPECIFIC INTERNATIONAL LAW

In the discussion on genomes, two camps of international lawyers have manifested at both sides of the spectrum. Those stressing the benefits of germ-line interventions interpret certain human rights provisions as being in favour of the procedure and say that ‘international human rights law does not go as far as the species preservation advocates sometimes claim.’⁵⁰ Opponents invoke the concept of human dignity and emphasise the biological dangers and ethical concerns connected to genomics. Trying to find out which side had the better arguments, I realized that at first sight the most relevant international human rights standards lent themselves to both sides of the argument⁵¹. An example for such a Janus-faced human right would be the right to health that could promote genomics for their potential to improve individual health and at the same time restrict genomics for their potential to diminish the fitness of the human species. Hence, both camps of lawyers seem to have their point. Other relevant rights, such as the right of future generations to be free of genetic alterations made without their consent, the child’s right to an untouched genetic inheritance or the collective human right to live in a world that is genetically diverse⁵² are recent appearances on the international stage and can hardly be regarded as recognized human rights. As we will see

⁴⁷ George J. Annas, Lori B. Andrews and Rosario M. Isasi, ‘Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations’ (2002) 28 *American Journal of Law and Medicine* 151, 173.

⁴⁸ *Treaty on the Non-proliferation of Nuclear Weapons*, opened for signature 1 July 1968, 729 UNTS 168 (entered into force 5 March 1970).

⁴⁹ Johann Wolfgang von Goethe, *The Sorcerer’s Apprentice* (1799) (Edwin Zeydel trans, 1955 ed) [trans of: Der Zauberlehrling] Virginia Commonwealth University <http://www.fln.vcu.edu/goethe/zauber_e3.html> at 21 October 2007.

⁵⁰ Marks, above n 11, 135.

⁵¹ So did Marks, *ibid* 122.

⁵² Above p 2.

later, particular difficulties arise when we invoke the rights and interests of future generations in order to limit human rights of living individuals.

The following analysis of regulations on biomedicine, particularly the 1997 Universal Declaration on the Human Genome and Human Rights,⁵³ the 1997 European Convention on Human Rights⁵⁴ and the 2005 Universal Declaration on Bioethics and Human Rights⁵⁵ is meant to reveal which rights their drafters considered significant and how they solved the problem of Janus-faced rights. In chapter III, a close look at the different rights will clarify whether the human rights framework lends more to a permissive or to a restrictive policy towards germ-line interventions. At first, however, I will show why germ-line interventions are a topic for international human rights law at all.

The Genome as an Object of Public International Law

Depictions of a future society of enhanced individuals have a tendency to dystopias such as Aldous Huxley's *Brave New World* or Andrew Niccol's *Gattaca*.⁵⁶ Unforeseeable biological consequences of an altered gene pool and social animosity triggered by genetic determinism are the major concerns that have hitherto limited unbridled scientific research. According to biologist Desmond S.T. Nicholl, the biological community has self-imposed regulations that limit the progress in contentious cases.⁵⁷ His answer to ethical concerns is a 'common sense and a solid regulatory framework.'⁵⁸ Such a regulatory framework, however, is not easily achieved, especially when 'there are no "correct" answers, as each must be addressed from the perspective of the individual, family, society, race or nation that is facing up to the situation.'⁵⁹ Several States such as Germany, Hungary, Norway or Israel have already implemented total bans on attempts to modify the germ-line, as mentioned above, the prohibition of germ-line interventions is even laid down in the Swiss constitution.⁶⁰ Other states such as Brazil, Finland or France make exceptions for the treatment of severe genetic defects or hereditary diseases.⁶¹ However, this patchwork of different solutions is not

⁵³ *Universal Declaration on the Human Genome and Human Rights*, above n 14.

⁵⁴ *Convention on Human Rights and Biomedicine*, opened for signature 4 April 1997, ETS No 164 (entered into force 1 December 1999).

⁵⁵ *Universal Declaration on Bioethics and Human Rights*, above n 16.

⁵⁶ See also the numerous references to dystopian novels in George J. Annas, 'Man on the Moon, Immortality, and Other Millennial Myths: The Prospects and Perils of Human Genetic Engineering' (2000) 49 *Emory Law Journal* 753.

⁵⁷ Nicholl, above n 4, 6.

⁵⁸ *Ibid* 176 and 262.

⁵⁹ *Ibid* 239.

⁶⁰ Article 119(2)(a): 'toute forme de clonage et toute intervention dans le patrimoine génétique de gamètes et d'embryons humains sont interdites,' *Constitution fédérale de la Confédération suisse*, above n 36.

⁶¹ See the list of legislation in force related to human species protection as to the year 2002 by Annas et al, above n 47, 174-8.

desirable. As a matter of fact, the natural spread of genetic material across national borders would soon introduce altered genomes into societies that have decided against germ-line interventions. Hence, Nicholl's suggestion to give authority over their genetic material to different units of society is a mixed blessing. An individual who secretly had his or her own genome changed could easily sabotage the sexual partner's decision not to take influence on his or her germ cells. On a global level, a permissive policy in some and a restrictive policy in other States would pose a new challenge to the international community. Conservative States would have to decide between the adoption of equally permissive regulations and the banishment of citizens from liberal States in order to protect their "national gene pool" from manipulated genomes. Article 19(4) of the Biodiversity Convention of 1992, which obliges States to provide 'any available information on the potential adverse impact of the specific organisms [resulting from biotechnology] concerned to the Contracting Party into which those organisms are to be introduced,'⁶² contains a less drastic rule for non-human material but is certainly not feasible for globe-trotting human beings. In addition, the gap between developing and industrialised countries might widen even more since genetic enhancement procedures will probably be available in developed countries first.⁶³ There can be no doubt that those scenarios would lead to an undesirable disintegration of nations.

Questions of genomics should therefore be solved, some might say: can only be solved, on an international level. So far, the discussion on the protection and beneficial use of the genome by the international community has spawned three major conventions and declarations, however, with differing content. Research workers feel that this 'multiplicity of standards and rules and the variability used to describe the same reality is detrimental' to their work and demand a harmonisation.⁶⁴ Different cultural and religious world-views render such an endeavour extremely difficult. As I will show now today's incoherent legal situation mirrors this complexity.

The 1997 European Convention on Human Rights and Biomedicine

The European Convention on Human Rights and Biomedicine was the first treaty to specifically deal with genomics. It allows modifications 'undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in

⁶² *Convention on Biological Diversity*, opened for signature 5 June 1992, 1760 UNTS 142, art 19(4) (entered into force 29 December 1993).

⁶³ See the according provisions in the *Universal Declaration on Bioethics and Human Rights*, above n 16, art 15, and the *Universal Declaration on the Human Genome and Human Rights*, above n 14, art 18.

⁶⁴ Bartha M. Knoppers and Clémentine Sallée, 'Ethical Aspects of Genome Research and Banking' in Christoph W. Sensen (ed) *Handbook of Genome Research* (2005) vol.2, 509, 510-1.

the genome of any descendants.’⁶⁵ Thus, it prohibits direct germ-line interventions. Since somatic cell interventions can have unwanted side effects on the germ-line, the convention only prohibits interventions *aimed* to modify germ cells. Even though therapeutic germ-line interventions were not generally excepted from the ban medical purposes were given due regard in some cases. For example, the convention allows the choice of a future child’s sex during medically assisted procreation if it serves the prevention of sex-related hereditary diseases.⁶⁶

From the explanatory report we can tell that despite the positive perspectives of direct germ-line interventions the drafters were more concerned about the biological danger for the human species and the production of ‘individuals or entire groups endowed with particular characteristics and required qualities.’⁶⁷ At the centre of the convention is the primacy of the human being over the sole interest of science or society.⁶⁸ It is the fundament for the numerous provisions that focus on the protection of individual persons from experimental or coercive treatments.⁶⁹ In connection with germ-line interventions, however, the pre-eminence of the individual cannot be the underlying concept since the individual interest to have healthy children would certainly favour them, so does the child’s interest to be born healthy. Conversely, the protection of the genome serves the higher cause of the protection of the human species and the prevention of societal tension. This allows the conclusion that the prohibition of germ-line interventions is a conceptual alien in a convention that otherwise emphasises the protection of the individual.

Unfortunately, neither the convention itself nor the explanatory report give a decent explanation for why the individuals’ interests have to give way to the interest of humanity as a whole in the context of germ-line interventions. The drafters’ wary approach to balance the pros and cons of germ-line interventions manifests only in the preamble of the convention where it says that ‘progress in biology and medicine should be used for the benefit of present and future generations.’⁷⁰ Considering that the preamble was meant to infer ‘that progress, human benefit and protection can be reconciled if public awareness is aroused’⁷¹ one would

⁶⁵ *Convention on Human Rights and Biomedicine*, opened for signature 4 April 1997, ETS No 164, art 13 (entered into force 1 December 1999).

⁶⁶ *Ibid*, art 14.

⁶⁷ *Convention on Human Rights and Biomedicine, Explanatory Report*, above n 25, para 89.

⁶⁸ *Ibid*, paras 14, 21-2.

⁶⁹ Most articles deal with the protection of people from interventions without consent (arts 5-9, 19, 22), collection and use of information (art 10), protection from discrimination (art11), research without consent (arts 15-18).

⁷⁰ *Convention on Human Rights and Biomedicine, Explanatory Report*, above n 25, para 14; *Convention on Human Rights and Biomedicine*, opened for signature 4 April 1997, ETS No 164, preamble (entered into force 1 December 1999).

⁷¹ *Convention on Human Rights and Biomedicine, Explanatory Report*, above n 25, para 15.

have hoped for a more detailed balancing of the human rights favouring and those opposing germ-line interventions. As mentioned before, such a discussion does not even appear in the explanatory report. As an optimist I would say that the lack of further debate makes the prohibition a definite authoritative tenet. However, an in depth consideration would certainly have enriched the discussion. It remains to say that of all the members of the Human Genome Project Consortium, only France has signed (but not ratified) the convention, while Germany, the United Kingdom, Japan and the United States have not.

The idea of an undisputed ban of germ-line interventions is supported by another European regulation. In 1998, the European Parliament and the Council of the European Union stated in the introductory remarks to Directive 98/44/EC that there was ‘a consensus within the Community that interventions in the human germ line [...] offends [sic] against *ordre public* and morality.’⁷² It therefore was ‘important to exclude unequivocally from patentability processes for modifying the germ line genetic identity of human beings.’⁷³ Although this statement does not constitute a prohibition of germ-line interventions, it reveals that there was a strong European call to ban them. As we will see now, relevant global regulations did not echo this call.

The 1997 Universal Declaration on the Human Genome and Human Rights

UNESCO’s General Conference adopted the Universal Declaration on the Human Genome and Human Rights more than six months after the Council of Europe’s Convention on Human Rights and Biomedicine had been signed. It bans practices contrary to human dignity but only reproductive cloning was expressly identified as such a practice.⁷⁴ The task of identifying others was left to States and competent international organisations.⁷⁵ Article 24 of the declaration addresses the topic of germ-line interventions and assigns the IBC to give advice ‘in particular regarding the identification of practices that could be contrary to human dignity, such as germ-line interventions.’ The German proposal to amend an explicit prohibition of germ-line interventions was rejected by the other States.⁷⁶

⁷² Directive 98/44/EC of the European Parliament and the Council of 6 July 1998 on the Legal Protection of Biotechnological Inventions [1998] OJ L 213/13, para 14.

⁷³ Ibid.

⁷⁴ Universal Declaration on the Human Genome and Human Rights, above n 14, art 11.

⁷⁵ Ibid.

⁷⁶ Lenoir, above n 17, 555-6.

Yet the declaration pays more attention to the conflict of interests than the Council of Europe's convention. Although it partially covers the same topics⁷⁷ it devotes a lot more time to the positive effects of genomics. Article 1 declares the human genome a common property or 'heritage of humanity' that 'underlies the fundamental unity of all members of the human family.'⁷⁸ By this, the declaration acknowledges that groups of people can have a collective human dignity⁷⁹ and implies that humankind, as a whole, has to take responsibility for both the benefits and the risks associated with genomics. In contrast to the Council of Europe's text, the declaration even endorses research, recognising the potential of genomics to improve the health of individuals and humankind, recognising also the freedom of research and the right to benefit from scientific progress.⁸⁰ At the same time, it warns of the ethical and social implications and highlights the need of an assessment of the risks and benefits pertaining to research on the human genome.⁸¹ In view of the cautious assessment of germ-line interventions in Article 24, however, it is surprising how the declaration explicitly encourages States to foster 'research on the identification, prevention and treatment of genetically based and genetically influenced diseases.'⁸² Thus, while there is merit in the convention's consideration of permissive and restrictive aspects, it remains a double entendre by avoiding a conclusion.

There are two plausible reasons for this condition. The first is the purpose of the declaration, which was to draft a statement of universal bioethical principles that 'generally does not directly address the details of the practices to which such principles might apply.'⁸³ Apparently, the appearance of cloning was an exception 'motivated by the drafters' reactions to the news of the cloned sheep "Dolly" in Scotland.'⁸⁴ The second, more relevant reason is UNESCO's more liberal attitude towards germ-line interventions. Already in the IBC's *Report on Human Gene Therapy* of 1994 the working group concluded that germ-line interventions 'should not be categorically disallowed.'⁸⁵ This was based on the assumption that some hereditary diseases were so grave that a benefit-cost analysis would justify their prevention even through risky germ-line interventions.⁸⁶ It is likely that the considerations

⁷⁷ *Universal Declaration on the Human Genome and Human Rights*, above n 14: the protection of people from research and treatment without consent (art 5), collection and use of information (art 7), protection from discrimination (art 6).

⁷⁸ *Ibid*, art 1.

⁷⁹ *Ibid*, art 10.

⁸⁰ *Ibid*, preamble and arts 12, 14, 15, 17.

⁸¹ *Ibid*, arts 13, 19(a)(i).

⁸² *Ibid*, art 17.

⁸³ Lenoir, above n 17, 555.

⁸⁴ *Ibid*.

⁸⁵ Edgar and Tursz, above n 37, 17.

⁸⁶ *Ibid*.

expressed in this report also tipped the scale against an explicit prohibition of germ-line interventions in the 1997 Universal Declaration.

In this climate of indefiniteness, some members of the Third Committee voiced disapproval before the UN General Assembly endorsed the declaration in Resolution 53/152.⁸⁷ The New Zealand delegate criticised that the declaration had been ‘adopted in haste,’ and others, such as the Argentinean delegate, expressed that the declaration was ‘far from closing the debate on the potential ethical implications of scientific and technological progress’ and ‘was simply a starting point for that debate.’⁸⁸ Said mandate to the IBC in Article 24 clearly underlines that statement’s validity. Regrettably, the IBC has drawn up only one according report so far⁸⁹ and its substance is questionable. Almost six years after the declaration had been adopted, the report merely quoted Article 24, repeating that ‘germ-line interventions *could be* contrary to human dignity.’⁹⁰ The working group found ‘no reason to date to modify this position.’⁹¹ Hence, the IBC virtually evaded the answer or at least postponed it. All aspects considered, the declaration presents itself much more open to genomics than the European convention and it addresses more of the controversial topics. Instead of condemning germ-line interventions categorically, it presents the pros and cons. The flipside is the declaration’s avoidance of a clear statement.

In the same year, UNESCO’s General Conference also adopted the Declaration of the Responsibilities of Present Generations towards Future Generations.⁹² Its Article 6 touches on the human genome and biodiversity, stating that

[t]he human genome, in full respect of the dignity of the human person and human rights, must be protected and biodiversity safeguarded. Scientific and technological progress should not in any way impair or compromise the preservation of the human and other species.

However, the recourse to indefinite wording leaves doubts as to the precise scope of the provision and does not contribute new aspects to the discussion. What can be said is that the

⁸⁷ *The Human Genome and Human Rights*, GA Res 53/152, UN GAOR, 53rd sess, 85th plen mtg, UN Doc A/RES/53/152 (1999).

⁸⁸ *Summary record of the 50th meeting*, UN GAOR, 53rd sess, 3rd Committee, [28,29], UN Doc A/C.3/53/SR.50 (1999).

⁸⁹ Galjaard, above n 35.

⁹⁰ *Ibid*, para 84 (emphasis added).

⁹¹ *Ibid*.

⁹² *Declaration of the Responsibilities of Present Generations Towards Future Generations*, adopted by the UNESCO General Conference at its 29th session, 27 November 1997, UNESCO Documents and Publications <<http://unesdoc.unesco.org/images/0011/001108/110827eb.pdf>> at 21 October 2007.

notions of protection of the genome and the prohibition to compromise the preservation of the human species seem to ban risky tampering with the genome, which could include germ-line interventions. Conversely, beneficial interventions would certainly be in the interest of future generations. In summary, we can state that the drafters of those two UNESCO documents of 1997 wanted to make clear that the beneficial effects of germ-line interventions for medical purposes were not to be ignored.

The 2005 Universal Declaration on Bioethics and Human Rights

In the Universal Declaration on Bioethics and Human Rights of October 2005⁹³ the IBC missed another opportunity to deal with the supposed conflict of germ-line interventions and human rights. While the text considers benefits and harms,⁹⁴ social responsibility and health⁹⁵ and the protection of biodiversity,⁹⁶ the provision dealing with the protection of future generations is rather short. It states that ‘[t]he impact of life sciences on future generations, including on their genetic constitution, should be given due regard.’⁹⁷ However, since the declaration was not meant to cover topics ‘already addressed by other instruments, notably the Universal Declaration on the Human Genome and Human Rights’⁹⁸ this shortness is somewhat understandable. In fact, despite its name the Declaration may not cover germ-line interventions at all. Support for this assumption comes from the explanatory memorandum, which speaks of the

responsibility towards the biosphere, [with regard to which] a special reference to future generations is made in the text to the safeguarding of interests in biodiversity and the biosphere that extend beyond the present generation.⁹⁹

This vague statement has hardly any significance for the question of how international law should handle germ-line interventions. In addition, ‘life sciences’ in Article 16 only refer to ‘any study or research discipline that contributes to the understanding of life processes.’¹⁰⁰

⁹³ *Universal Declaration on Bioethics and Human Rights*, above n 16.

⁹⁴ *Ibid*, art 4.

⁹⁵ *Ibid*, art 14.

⁹⁶ *Ibid*, art 17.

⁹⁷ *Ibid*, art 16.

⁹⁸ *Explanatory Memorandum on the Elaboration of the Preliminary Draft Declaration on Universal Norms on Bioethics*, First Intergovernmental Meeting of Experts Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics, UNESCO Headquarters, 4-6 April 2005, [27], UNESCO Doc SHS/EST/05/CONF.203/4 (2005).

⁹⁹ *Ibid*, para 86.

¹⁰⁰ *Ibid*, para 19.

This definition does not fit germ-line interventions, which require the understanding of life processes more than they contribute to it.

Conclusion

Not much has changed since Iulia-Antoanella Motoc presented her expanded working paper on human rights and bioethics to the Sub-Commission on the Promotion and Protection of Human Rights of the UN Economic and Social Council. In 2003, she wrote that ‘[t]aken together, the norms relating to the human genome form an incoherent picture.’¹⁰¹ My analysis has so far confirmed this perception. While the European Convention on Human Rights and Biomedicine provides us with an unambiguous statement without further explanation, the Universal Declaration on the Human Genome and Human Rights goes into the discussion but evades a conclusion. This situation could be the result of their legal nature, the first being an international treaty, the second being a non-binding political declaration providing guidelines more than proscribing specific behaviour. Apart from that, the texts by UNESCO and the IBC undoubtedly convey a more open-minded attitude towards medical germ-line interventions than their European counterpart. In the light of the mandate to the IBC to determine if germ-line interventions violate human dignity, the following chapter shall position germ-line interventions in the present framework of human rights and human dignity.

IV. GENOMICS AND INTERNATIONAL HUMAN RIGHTS LAW

As noted earlier, human rights are ambiguous when used as arguments for or against genomics. However, ‘[m]uch of the extant literature on ethical and social issues is concerned with “freedoms from...”’,¹⁰² somewhat ignoring that there also might be “freedoms to” that favour genetic engineering. Declarations and treaties such as the 1948 Universal Declaration of Human Rights (UDHR),¹⁰³ the 1966 International Covenants of Economic, Social and Cultural Rights (ICESCR)¹⁰⁴ and of Civil and Political Rights (ICCPR),¹⁰⁵ the 1989 Convention on the Rights of the Child (CRC)¹⁰⁶ and the 1975 Declaration on the Rights of Disabled Persons¹⁰⁷ are relevant sources for the latter. They emphasise the primacy of individual liberties, the need to increase health and living standards, the necessity of preventing disabilities and the responsibility to provide offspring with the best possible

¹⁰¹ Motoc, above n 5, para 5.

¹⁰² Buchanan et al, above n 3, 309.

¹⁰³ *Universal Declaration of Human Rights*, above n 13, arts 26(3) and 29(2).

¹⁰⁴ *International Covenant of Economic, Social and Cultural Rights*, adopted by UNGA Res 2200(XXI) (1966), 993 UNTS 3, art 12 (entered into force 3 January 1976).

¹⁰⁵ *International Covenant of Civil and Political Rights*, adopted by UNGA Res 2200(XXI) (1966), 999 UNTS 171, art 7 (entered into force 23 March 1976).

¹⁰⁶ *Convention on the Rights of the Child*, adopted by UNGA Res 44/25 (1989), 1577 UNTS 3, arts 18, 23(4), 24(1) and (2), 27 (entered into force 2 September 1990).

¹⁰⁷ *Declaration on the Rights of Disabled Persons*, GA Res 3447 (XXX), UN GAOR, 30th sess, 2433rd plen mtg, UN Doc A/RES/3447(XXX) preamble (1976).

opportunities. Ironically, it is just the supposedly “forbidden fruit” of germ-line interventions that provides the most promising means to achieve those goals. On the other hand, germ-line interventions raise questions of human dignity and the potential jeopardy to future generations. What is the position of human rights law towards this conflict of interests? In the following paragraphs I will show that only the freedom of scientific research and the right to enjoy the benefits thereof support germ-line interventions. It will also become obvious that the recognition of rights of future generations in today’s human rights law is questionable. Nonetheless, considering the States’ unanimous opposition against germ-line interventions for non-therapeutic purposes, I will conclude that the freedom of scientific research and the right to enjoy its benefits are limited to supporting therapeutic germ-line interventions only. The draft declaration in the appendix to this article is meant to clarify the current situation. However, we should bear in mind that different moral and ethical convictions often determine the interpretation of legal texts. Therefore, I will attempt to stay as objective as possible in my analysis and give room to the full range of possible understandings. For further clarity, the following rights and freedoms are grouped in those that arguably support and those that arguably oppose germ-line interventions.

Germ-line Interventions and Permissive International Human Rights Law

Human autonomy stands in the centre of the human rights framework, which seeks to prevent the State’s interference with personal liberties and bodily integrity and to guarantee access to social and economic resources.¹⁰⁸ Thus, human rights help individuals defend their integrity against public authorities. Sometimes, they also order States to provide individuals with the means to realise their rights. In the context of genomics, both aspects of human rights law are relevant. Procreative liberties and the freedom of scientific research could oppose a prohibition of germ-line interventions, while some rights of the child, the right to health and the right to benefit from scientific progress could require the provision of access to beneficial genomic technologies. Unless otherwise indicated, the following rights are to be interpreted as *prima facie* and thus subject to being limited by the opposing rights that will be dealt with in the second half of this chapter. At first, however, we will take a closer look at the concept of consent since human autonomy includes the freedom to consent even to perilous treatments.

¹⁰⁸ Iles, above n 10, 28.

(1) Consent

Article 7 of the ICCPR states that ‘no one shall be subjected without his free consent to medical or scientific experimentation.’¹⁰⁹ Even though the provision covers hideous ‘criminal experiments on human beings such as those committed in Nazi concentration camps’¹¹⁰ the individual may still choose deliberately to undergo such a procedure. ‘Free consent’ means that individuals seem to be free to do what they wish to their bodies.¹¹¹ For this reason, the Universal Declaration on the Human Genome and Human Rights¹¹² and the European Convention on Bioethics and Human Rights¹¹³ provide that genetic treatment is subject to an individual’s prior, free and informed consent. Hence, every person could have the right to consent to germ-line interventions. The distinctive feature of germ-line interventions, however, is that they do not affect living individuals but their offspring. The question is now whether parents can consent on behalf of their unborn children. Although most international regulations contain articles on consent, they do not cover this specific aspect.

With regard to Article 7 of the ICCPR, the UN Human Rights Committee showed general reluctance to allow a third party to consent on behalf of another person to any medical or scientific experimentation that may be detrimental to that person’s health, even if he or she was not capable of giving valid consent his- or herself.¹¹⁴ Due to this narrow interpretation of the provision it is unlikely to cover the consent on behalf of unborn children. By the same token, the Universal Declaration on the Human Genome and Human Rights makes arrangements for the case that according to the law a person does not have the capacity to consent,¹¹⁵ but the wording leaves no doubt that this only applies to living persons. The declaration further covers the situation where a person is not in the position to consent, in which case consent or authorization shall be obtained in the manner prescribed by law, guided by the person’s best interest.¹¹⁶ Although one might argue that an unborn child is not *in the position* to consent, Noëlle Lenoir, Chair of the IBC during the drafting of the declaration, points out that the provision is related ‘to sick or very young children.’¹¹⁷ In summary, we can say that consent as a legal construct that allows parents to decide on behalf of their future

¹⁰⁹ *International Covenant of Civil and Political Rights*, adopted by UNGA Res 2200(XXI) (1966), 999 UNTS 171, art 7 (entered into force 23 March 1976).

¹¹⁰ Manfred Nowak, *U.N. Covenant on Civil and Political Rights, CCPR Commentary* (1993) art 7, para 29.

¹¹¹ Annas, above n 56, 768; Iles, above n 10, 119.

¹¹² *Universal Declaration on the Human Genome and Human Rights*, above n 14, art 5.

¹¹³ *Convention on Human Rights and Biomedicine*, above n 15, arts 5-9.

¹¹⁴ Human Rights Committee, *General Comment 20/44 of 3 April 1992*, para 7, reproduced in Nowak, above n 110, 871-2.

¹¹⁵ *Universal Declaration on the Human Genome and Human Rights*, above n 14, art 5(e).

¹¹⁶ *Ibid*, art 5 (b).

¹¹⁷ Lenoir, above n 17, 563.

children is unknown to international law. That is not to say that they do not have their own rights to carry out germ-line interventions, which could derive from their procreative liberties.

(2) Procreative Liberties

The explanatory report to the European Convention on Bioethics and Human Rights states that parents have a right to carry out predictive genetic tests at the embryonic stage to find out whether an embryo carries hereditary traits that will lead to serious diseases in the future child.¹¹⁸ Should they not also have a right to take other counter-measures, especially when the alternative would be the abortion of the pregnancy? The European convention answers in the negative. Yet from a moral point of view, procreative liberties are extremely far-reaching. As a central part of many people's life-plan, procreative liberties deserve a strong measure of respect in all reproductive activities.¹¹⁹ Among them, seeking to have healthy children and preventing severe birth defects are key aspects.¹²⁰ Those who support the idea that the parents' moral rights over their children cover germ-line interventions often underpin their argument under reference to the parents' far-reaching discretion once a child is born. Societies expect parents to keep their offspring away from harmful activities and influences, to have them vaccinated against common childhood diseases and maybe even to insure that they maintain a balanced diet.¹²¹ At the same time, most societies respect pluralism and allow parents broad discretion to determine what is best for their children. Eventually, parents shape their children's corporal and mental abilities through the environment they provide.¹²² Designing the offspring's genome could therefore be regarded as an additional factor to support their health and development. Moral concerns would be sidelined. From a moral point of view, the child's question "Who would I have been if my parents had not selected red hair for me before my birth?" seems as reasonable as the question "Who would I have been if my parents had not made me eat vegetarian food all the time after my birth".¹²³ Nevertheless, parents are not entitled to impose all their idiosyncratic attitudes and wishes on their children. They are not allowed to narrow their opportunities beyond a reasonable standard, i.e. they must leave the child with a range of opportunities to create his or her own plan of life.¹²⁴

¹¹⁸ *Convention on Human Rights and Biomedicine, Explanatory Report*, above n 25, para 83.

¹¹⁹ Robertson, above n 32, 4.

¹²⁰ *Ibid* 150+161.

¹²¹ Buchanan et al, above n 3, 157; Robertson, *ibid* 164.

¹²² Pentii Arajärvi, 'Article 26' in Gudmundur Alfredsson and Asbjørn Eide (eds) *The Universal Declaration of Human Rights* (1999) 551, 556; see also article 5 of the CRC, dealing with appropriate guidance of a child by his or her parents, at: *Convention on the Rights of the Child*, adopted by UNGA Res 44/25 (1989), 1577 UNTS 3, art 5 (entered into force 2 September 1990).

¹²³ See Buchanan et al, above n 3, 160-1.

¹²⁴ *Ibid* 208, 171 and 175.

Apart from that restriction, there seems to be no moral objection to parents using genetic interventions to produce the best offspring they can.¹²⁵ But what is the best? And the best for whom, anyway? Social pressure of group inclusion and exclusion could unwittingly control parental decisions. Choice could turn into obligation whenever parents fear that they themselves or their children could become misfits if they refrain from germ-line interventions. This is why some scholars conclude that '[r]eproductive freedom and the liberty to construct and conduct a family life are potentially both enhanced and threatened by the genetic revolution.'¹²⁶

It difficult to tell whether human rights have adopted the extensive moral scope of procreative liberties. Due to the vague wording of relevant provisions, the 'content of reproductive rights remains hazy in international legal discourse.'¹²⁷ As seen before, this vagueness is a common condition in the realm of procreative liberties in the human rights framework particularly with regard to genetic manipulations. A well-established human right is the right to found a family, laid down in Article 16 of the UDHR and Article 23(2) of the ICCPR. While the texts remain silent on what the right to found a family comprises, it is the common understanding that it obliges States not to interfere in relationships and to provide couples with the possibility of institutionalising their relationship.¹²⁸ Whether it comprises the right to have a child is controversial in the case of Article 16 of the UDHR,¹²⁹ but recognized as a core aspect of Article 23(2) of the ICCPR.¹³⁰ The right supposedly covers both a State's non-interference in procreation as well as the provision of access to techniques of artificial procreation.¹³¹ Legal restrictions are feasible but subject to thorough justification in the face of procreative liberties. However, restrictions of the right are likely to be permissible when it comes to 'forms of genetic manipulation and experiments with embryos in the womb or *in vitro*.'¹³² In brief, the right to found a family covers access to artificial procreation but not necessarily to genetic modifications.

The 1994 International Conference on Population and Development in Cairo constitutes a rare exception to the right's usual haziness. The conference report held that 'reproductive rights embrace certain human rights that are already recognized in national

¹²⁵ Ibid 181; Robertson, above n 32, 172.

¹²⁶ Buchanan et al, ibid 321.

¹²⁷ Aditi Gowri, 'Reproduction, Rights and Public Policy: A Framework for Assessment' (2000) 35 *Texas International Law Journal* 13, 13.

¹²⁸ Stéphanie Lagoutte and Ágúst Thór Árnasson, 'Article 16' in Gudmundur Alfredsson and Asbjørn Eide (eds) *The Universal Declaration of Human Rights* (1999) 325, 340

¹²⁹ Ibid.

¹³⁰ Nowak, above n 110, art 23 para 28.

¹³¹ Ibid, para 29.

¹³² Ibid, para 30.

laws, international human rights documents and other consensus documents.¹³³ Subsequently, the report enumerated these rights and identified a ‘basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so.’¹³⁴ It also claimed the existence of a ‘right to attain the highest standard of sexual and reproductive health,’ which includes the parents’ ‘right to make decisions concerning reproduction free of discrimination, coercion and violence.’¹³⁵ While these rights appear to focus more on the right to procreate at all than on a supposed right to a certain quality of the fruit of procreation, the report also touches upon the topic of the healthiest offspring possible. It indicates a ‘right of access to appropriate health-care services that will [...] provide couples with the best chance of having a healthy infant.’¹³⁶ Undoubtedly, we could define germ-line interventions as a (future) health-care service that enhances the chances to give birth to a fit child. However, two aspects show us that this supposed right does not necessarily cover or demand germ-line interventions. First, using the words “best chance” reveals that chance shall still be the dominant factor not intended genetic interventions. Second, the report regarded the exercise of those rights as subject to responsible exercise, especially to the parents’ responsibilities towards the community.¹³⁷ This rather vague exception certainly leaves broad discretion to States when they decide to limit procreative liberties. As for Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms,¹³⁸ which also contains the right to found a family, some commentators say, that as far as artificial reproduction is concerned,

[i]t does not seem likely that the Convention imposes any limits on what choices a state may make and it is probably premature to decide that the Convention imposes a positive obligation on a state to legislate to allow any particular technique.¹³⁹

We can say the same about germ-line interventions. Considering the controversy on those interventions, it is very unlikely that States would have difficulties to argue that germ-line interventions are not part of the right to found a family, which focuses on the right to have children rather than a right to have the “best possible” children. Then again, the right to have a

¹³³ *Report of the International Conference on Population and Development, Cairo, 5-13 September 1994*, [7.3], UN Doc A/CONF.171/13 (1994).

¹³⁴ *Ibid.*

¹³⁵ *Ibid.*

¹³⁶ *Ibid.*, para 7.2.

¹³⁷ *Ibid.*, para 7.3.

¹³⁸ *Convention for the Protection of Human Rights and Fundamental Freedoms*, opened for signature 4 November 1950, ETS No 5, art 12 (entered into force 3 September 1950).

¹³⁹ D.J. Harris, M. O’Boyle and C. Warbrick, *Law of the European Convention on Human Rights* (1995) 441.

child could be invoked in the context of germ-line interventions in borderline cases where a hereditary disease would inevitably render a couple's offspring seriously impaired and therefore would prevent them from having children at all. In those cases, a germ-line intervention could be the only way to exercise the right to have a child. However, in those cases States could fulfil their human rights obligations by providing procedures of adoption.¹⁴⁰

In summary, the vagueness of procreative liberties in international law hinders the recognition of a right to germ-line interventions. While it is one thing to deny parents the right to genetic interventions on their offspring, it is another thing to deny children the right to a health and opportunities from the moment of their birth.

(3) The Rights of the Child and Future Generations

Ten fingers, ten toes.

That was all that used to matter.¹⁴¹

Every year, more than seven million children around the world are born with severe genetic disorders or birth defects.¹⁴² Around 90 per cent of them are born in mid- and low-income countries, however, genetic and congenital disorders are also the second most common cause of infant and childhood death in the developed world.¹⁴³ Those numbers make it obvious why germ-line interventions are a subject of great hopes. As mentioned earlier, societies usually expect parents to wish and do the best for their child. Nowadays, prenatal interventions to cure diseases or defects are quite common. The surgery on an embryo's heart to save his or her life, for example, is ethically uncontroversial. This is not the case in the context of genomics where it is feared that children will become 'objects or products chosen on the basis of their qualities, [...], valued not for themselves but for the pleasure and satisfaction they will give parents.'¹⁴⁴ As we will see in a later chapter, such an attitude could conflict with human dignity. Conversely, the prevention of hereditary diseases cannot be dismissed as a solely egoistic parental act. A child, genetically disburdened of a severe disease, would probably approve this genetic manipulation. Such an intervention would

¹⁴⁰ Nowak, above n 110, art 23 para 30; Lagoutte and Árnasson, above n 128, 341.

¹⁴¹ Andrew Niccol, *Gattaca, early draft* (1997) The Daily Script
<http://www.dailyscript.com/scripts/gattaca_early.html> at 21 October 2007.

¹⁴² *Control of Genetic Diseases*, above n 38, para 4.

¹⁴³ *Ibid.*

¹⁴⁴ Robertson, above n 32, 150.

certainly appear less invasive to him or her than curfews, diets, violin lessons or any other educational measures parents are legally entitled to impose on their children. A child might even blame (and sue?) parents for not having prevented an inherited disease. This is why many people think that the prevention of a disease that stands in the way of most or nearly any plan of life is not objectionable from a moral point of view.¹⁴⁵

In the human rights framework, the rights of the child are compiled in the Convention on the Rights of the Child.¹⁴⁶ Important for the discussion on genomics are the rights related to health of Article 24, the right to life, survival and development of Article 6, and the right to an adequate standard of living, Article 27. However, the object of protection of the CRC is the child after birth (in any case not earlier than after the moment of conception¹⁴⁷) and the application of the CRC to future offspring bears some conceptual difficulties. While it 'may not matter much whether action is based on a right to protection for the unborn child or the right of the born child to have a healthy beginning'¹⁴⁸ it is certainly relevant for the application of the CRC that germ-line interventions take place before the conception of a child. Without the recognition of general obligations to un-conceived future generations it is a heavy burden to overcome this oddity and acknowledge a child's right to the eradication of hereditary diseases from the CRC. Strictly speaking, the CRC is not applicable. From the drafters' point of view, this is a reasonable consequence since the child would have to claim retroactively a right not to be born in the way he or she actually was.

However, at least Article 24(2)(f) of the CRC implies the existence of a right that comes into effect before the child is conceived. The norm demands that States take appropriate measures to develop preventive health care and family planning education and services in order to implement the child's right to health. Family planning includes, for example, the counselling concerning the risk of child death associated with childbearing by teenagers or with short-term inter-birth intervals.¹⁴⁹ Since preventive measures against those risks and according counselling can take place only before the conception of a child, the object of protection must be a potential child. Hence, we can conclude from Article 24(2)(f) that international obligations towards potential children are conceivable, albeit not the rule under the CRC. Nonetheless, the CRC does not recognise a child's right to be free of hereditary diseases. The opposite view would certainly be a misinterpretation of the CRC

¹⁴⁵ Buchanan et al, above n 3, 168; *WHO-Report*, above n 43, 168-9.

¹⁴⁶ *Convention on the Rights of the Child*, adopted by UNGA Res 44/25 (1989), 1577 UNTS 3 (entered into force 2 September 1990).

¹⁴⁷ Sharon Detrick, *A Commentary on the United Nations Convention on the Rights of the Child* (1999) 53-7.

¹⁴⁸ Thomas Hammarberg 'Children' in Asbjørn Eide, Catarina Krause and Allan Rosas (eds) *Economic, Social and Cultural Rights* (2nd ed, 2001) 353, 358.

¹⁴⁹ Detrick, above n 147, 414.

since an according proposal to extend the protection of the CRC to the conceived but unborn child¹⁵⁰ was not adopted and the ambit of the objects of protection must therefore be interpreted narrowly.

Ignoring this objection for one moment, I want to show now that even with a radical interpretation of the obligations of the CRC we could not derive a right to germ-line interventions from the CRC at all. The child's right to life in Article 6(1) of the CRC does not cover a right to a certain kind of life, nor does Article 27 entitle to certain living conditions beyond the environmental sphere of adequate food, clothing and housing.¹⁵¹ However, special mention needs to be made of Article 6(2) of the CRC, the right to survival and development. The rule obliges States to take positive steps to prolong the life of the child and to promote measures and conditions for his or her survival and development.¹⁵² Since severe diseases threaten the survival and hamper the development of the child, germ-line interventions provide the means to comply with the requirements of Article 6(2). The fact that States shall pursue those goals 'to the maximum extent possible'¹⁵³ further supports the argument for germ-line interventions. Conversely, the *travaux préparatoires* demand a different interpretation of this last phrase. Apparently, it was meant to indicate that States are allowed to consider economic, social and cultural conditions,¹⁵⁴ hence that they are entitled to consider a broad range of measures instead of being obliged to maximise the effects of single actions. The fact that the obligatory periodic reports on adopted measures only demand information about specific measures concerning the broad categories of the 'physical, mental, spiritual, moral, psychological and social development,' preparing the child for an 'individual life in a free society'¹⁵⁵ underpins this argument. Once again, the rule's vagueness prevents us from regarding Article 6(2) of the CRC as an obligation for States to provide access to germ-line interventions.

Less vague than this norm is Article 24 of the CRC that contains the right to the enjoyment of the highest attainable standard of health. It added some innovative provisions to the general right to health of Article 12 of the ICESCR, which makes it worth mentioning at this stage. One of the special features of Article 24 is the demand for measures to combat

¹⁵⁰ *Written statement submitted by the World Association of Children's Friends*, [1], UN Doc E/CN.4/1989/WG.1/NGO/1 (1989).

¹⁵¹ Detrick, above n 147, 458.

¹⁵² *Report of the Working Group on a Draft Convention on the Rights of the Child*, [18-19, 22], UN Doc E/CN.4/1988/28 (1988).

¹⁵³ *Convention on the Rights of the Child*, adopted by UNGA Res 44/25 (1989), 1577 UNTS 3, art 6(2) (entered into force 2 September 1990).

¹⁵⁴ Detrick, above n 147, 131-2.

¹⁵⁵ *General Guidelines Regarding the Form and Contents of Periodic Reports to be Submitted by States Parties Under Article 44, Paragraph 1 (b), of the Convention*, adopted by the Committee on the Rights of the Child, 343rd meet, 13th sess, [40], UN Doc CRC/C/58 (1996).

diseases through the application of readily available technology.¹⁵⁶ The provision especially covers the situation of children in developing countries lacking basic supplies of food and health care.¹⁵⁷ The combat of diseases therefore includes, *inter alia*, the immunisation against the common childhood diseases.¹⁵⁸ Could this comprise a “genetic immunisation” once the technology is available? Quite accurately, some philosophers draw parallels between germ-line interventions enhancing the immune system and ordinary vaccinations.¹⁵⁹ In neither case the child is asked for his or her consent but parents would make the decision with regard to the best interests of the child. The special emphasis on children’s health is also found in Article 12(2)(a) of the ICESCR that demands that States take steps necessary for the healthy development of the child. All aspects considered these norms have the potential to form a child’s right to be freed from hereditary diseases by germ-line interventions. However, supporters of such a right would have to wait until germ-line interventions have become a readily available technology whose risk-benefit ratio equals the one of immunisations against common childhood diseases. In addition, the parallel between immunisations and germ-line intervention only covers therapeutic germ-line interventions. Of course, the conceptual oddity of rights of non-existent children remains. For this, Article 3(1) of the CRC could provide a loophole, stating that the best interests of the child shall be a primary consideration for all actions concerning children. The norm also is a guideline to ‘evaluate laws, practices, and policies relating to children that are not covered by express obligations in the [CRC].’¹⁶⁰ Hence, the “best interest of the child”-doctrine could have influence also on the question of germ-line interventions and the rights of future generations.

Regrettably from the future generations’ point of view, the objects of protection of today’s international human rights law are identifiable individuals only. The idea of rights of future generations has gained little recognition in international law. It was regretted by some scholars that, despite its objective, the Declaration of the Responsibilities of Present Generations towards Future Generations¹⁶¹ is absent from the idea of *rights* of future generations and limited to moral responsibilities.¹⁶² However, without venturing too far into the realm of philosophy, one can say that the concept of rights of future generations is

¹⁵⁶ *Convention on the Rights of the Child*, adopted by UNGA Res 44/25 (1989), 1577 UNTS 3, art 24(2)(f) (entered into force 2 September 1990).

¹⁵⁷ Detrick, above n 147, 409.

¹⁵⁸ *Ibid.*

¹⁵⁹ Buchanan et al, above n 3, 154; Philip Kitcher, *The Lives to Come* (1996) 124.

¹⁶⁰ P. Alston and B. Gilmour-Walsh, *The Best Interest of the Child: Towards a Synthesis of Children’s Rights and Cultural Values* (1996) 37.

¹⁶¹ Above n 92.

¹⁶² UNESCO, *Final Report of the 8th Session of the Annual Meeting of Directors of Human Rights Institutes, Paris, 6-7 March 1997*, [21], UNESCO Doc SHS-97/CONF.013/3 (1997).

plausible.¹⁶³ At least international environmental law recognises obligations towards future generations to some extent in the form of the common heritage of humankind principle (CHH).¹⁶⁴ The CHH governs the deep-sea beds, Antarctica, the moon and other celestial bodies, and certain worldwide historical sites. Nowadays, there is a noticeable movement to declare the human genome a common heritage of humankind.¹⁶⁵ The Universal Declaration on the Human Genome and Human Rights, for example, proclaims that the genome, ‘[i]n a symbolic sense, [...] is the heritage of humanity.’¹⁶⁶ The problem of the CHH, however, is that it does not dictate conclusive results. The interpretations of the scope and consequences of the CHH vary considerably, shaped by ideology, legal philosophy and political bias.¹⁶⁷ Consequently, some argue that the application of the CHH to the genome would entail, *inter alia*, that all States share the responsibility for setting regulations and laws for permissible uses of the genome.¹⁶⁸ Others conclude that it would disavow state sovereignty, and mandate that the benefits be allocated to all humankind, including future generations.¹⁶⁹ Both approaches imply that beneficial interferences with the genome are permissible. In the same vein, Melissa Sturges included in her proposed treaty for the application of the CHH to the genome the ‘prohibition of an alteration of genes for any purpose except that which is necessary for the prevention of a deadly disease.’¹⁷⁰ However, she was ambivalent concerning how deadly a disease needs to be to fall under the exception.¹⁷¹ Apart from its uncertainty, the application of the CHH on the human genome meets with other criticism. The parallel that is drawn between the traditional objects of protection and the genome is not conclusive. While the moon and Antarctica do not have a natural link to a person or a nation, every genome is intrinsically tied to a human individual who could claim the prerogative to govern his or her genome. Hence, the CHH cannot cope with individuals who want to tamper with their own genetic material. Altogether, even though the application of the CHH would entail every States’ obligation to consider the interests of future generations, the CHH does not suffice to form an obligation to provide access to germ-line interventions for the good of future generations.

¹⁶³ See generally Ernest Partridge, *On the Rights of Future Generations* (1990) Institute for Global Communications <<http://gadfly.igc.org/papers/orfg.htm>> at 21 October 2007; Thomas Schwartz, ‘Obligations to Posterity’ in Richard I. Sikora and Brian M. Berry (eds) *Obligations to Future Generations* (1978) 3-13.

¹⁶⁴ Spectar, above n 9, 12; Edith Brown Weiss, *In Fairness to Future Generations: International Law, Common Patrimony, and Intergenerational Equity* (1989) 47-50.

¹⁶⁵ Motoc, above n 5, paras 7-14; see especially Spectar, above n 9, 8; Sturges, above n 9.

¹⁶⁶ *Universal Declaration on the Human Genome and Human Rights*, above n 14, art 1.

¹⁶⁷ Spectar, above n 9, 8.

¹⁶⁸ Motoc, above n 5, para 9.

¹⁶⁹ Spectar, above n 9, 8.

¹⁷⁰ Sturges, above n 9, 258, n218.

¹⁷¹ *Ibid.*

Hence, subject to the conceptual difficulties and quite far from traditional interpretations, a child's right to health could promote the legality of germ-line interventions. I will now try to verify this assumption in connection with the general right to health.

(4) The Right to Health

Since germ-line interventions are intended to improve the offspring's health it is natural that the human right to the enjoyment of the highest attainable standard of physical and mental health plays a pivotal role in the discussion. Article 12 of the ICESCR provides the most comprehensive codification of the right to health in international human rights law. Its second paragraph enumerates some of the steps to be taken by States to achieve the full realisation of the right. This includes the 'prevention, treatment and control of epidemic, endemic, occupational and other diseases.'¹⁷² At first sight, this provision could cover germ-line interventions since they make it possible to eradicate hereditary diseases. From a moral point of view, '[j]ustice may require genetic interventions to prevent disabilities because equality of opportunity is a component of justice and disabilities limit people's opportunities.'¹⁷³ Legally, however, the lack of conceptual clarity as to the content and scope of the right¹⁷⁴ makes it difficult to derive clear-cut obligations from it. Nevertheless, the call for an affirmation of the human right to health creating 'an obligation on the part of states and non-state entities alike to act in good faith to spread the life-saving benefits of the genome to all humankind'¹⁷⁵ is loud. Since the ICESCR does not contain rights of future generations, the derivation of a right to germ-line interventions meets the same conceptual difficulties we have encountered in connection with the CRC. Hence, the following analysis is once again subject to severe conceptual objections.

For obvious practical reasons, States cannot guarantee good health and people cannot claim a human right to *be healthy*. The broad term "right to health" covers various aspects including the right to health care and to a number of underlying preconditions for health, such as safe drinking water and adequate sanitation.¹⁷⁶ In fact, it is a right 'to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest

¹⁷² *International Covenant of Economic, Social and Cultural Rights*, adopted by UNGA Res 2200(XXI) (1966), 993 UNTS 3, art 12(2)(c) (entered into force 3 January 1976).

¹⁷³ Buchanan et al, above n 3, 287.

¹⁷⁴ Pridan-Frank, above n 18, 656.

¹⁷⁵ Spectar, above n 9, 39.

¹⁷⁶ Birgit Toebes, 'The Right to Health' in Asbjørn Eide, Catarina Krause and Allan Rosas (eds) *Economic, Social and Cultural Rights* (2nd ed, 2001) 169, 169.

attainable standard of health.¹⁷⁷ States therefore have ‘to take positive measures that enable and assist individuals and communities to enjoy the right to health,’ e.g. through immunisation programmes against the major infectious diseases.¹⁷⁸ Whether the prohibition of germ-line interventions conflicts with Article 12 of the ICESCR depends once again on the scope of the right to health.

In order not to make the right a comprehensive but meaningless paper tiger, efforts have been made to define a core content of the right to the highest attainable standard of health.¹⁷⁹ Though not uncontested, the core obligations comprise a healthy environment, the non-discriminatory access to health services, a minimum of food supply and nutrition, the provision of essential drugs and immunisation against the major infectious diseases as well as the appropriate treatment of common diseases and injuries.¹⁸⁰ According to the UN Committee on Economic, Social and Cultural Rights, the prevention, treatment and control of epidemic and endemic diseases and the immunization against the major infectious diseases occurring in the community are not part of but have comparable priority to the core obligations.¹⁸¹ The Committee found that the control of diseases as laid down in Article 12(2)(c) of the ICESCR refers to

States’ individual and joined efforts to, *inter alia*, make available relevant technologies, using and improving epidemiological surveillance and data collection on a disaggregated basis, the implementation or enhancement of immunization programmes and other strategies of infectious disease control.¹⁸²

Two aspects of the Committee’s general comment deserve closer attention. First, the wording of the provision as well as the Committee’s interpretation entirely focus on infectious diseases and epidemics rather than hereditary diseases. Second, it is quite significant for our topic that the Committee derives from the right to health not more than the obligation to refrain from ‘prohibiting or impeding *traditional* preventive care, healing processes and medicines.’¹⁸³ In conjunction with the already limited scope of core obligations, it seems that the right to health

¹⁷⁷ *Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights, General Comment No. 14*, Committee on Economic, Social and Cultural Rights, 22nd sess, 25 April – 12 May 2000, [9], UN Doc E/C.12/2000/4 (2000) (‘*General Comment No. 14*’).

¹⁷⁸ *Ibid*, paras 34 and 37.

¹⁷⁹ *Ibid*, paras 43-49.

¹⁸⁰ Toebes, above n 176, 177.

¹⁸¹ *General Comment No. 14*, above n 177, para 44.

¹⁸² *Ibid*, para 16.

¹⁸³ *Ibid*, para 34 (emphasis added).

would not stand in the way of a prohibition of the controversial *future* technique of germ-line interventions.

Apart from this widely accepted reading and the identification of core obligations, the wording of Article 12(1),(2)(c) of the ICESCR promises a broader scope of application, laying down the majestic and inspiring idea of a right to the *highest attainable* standard of health realized, *inter alia*, by the prevention of diseases. The genetic eradication of a diseased gene would certainly mean an important contribution to the highest attainable standard of health, not only for one individual but also for the whole family line. In a recent report, the secretariat of the WHO suggested that

[t]he control of genetic diseases should be based on an integrated and comprehensive strategy combining *best possible treatment and prevention* through community education, population screening, genetic counselling and the availability of early diagnosis.¹⁸⁴

This means that prevention is meant to be achieved by empowering couples to make their own informed procreative decisions through genetic counselling, e.g. the detection of genetic risks or the encouragement of reproduction at optimal maternal ages.¹⁸⁵ As far as genetic interventions are concerned, the report shortly refers to the future possibilities of somatic-cell gene therapy and states that ‘it will take years before this becomes clinical practice.’¹⁸⁶

It is quite significant that a report on the control of genetic diseases by the WHO, which was the first organization to formulate an explicit right to health,¹⁸⁷ takes no notice of germ-line interventions at all. In general, the WHO seem to be rather reluctant to pay a great deal of attention to germ-line interventions mainly because it considers them a distant prospect. With no sufficient knowledge on actual benefits and risks the organisation regards any judgement as premature,¹⁸⁸ while ‘claims for the medical benefits of genomics have undoubtedly been exaggerated, particularly with respect to the time-scales required for them to come to fruition.’¹⁸⁹ It speaks volumes that the WHO as an organisation that has dedicated

¹⁸⁴ *Control of Genetic Diseases*, above n 38, para 6 (emphasis in original).

¹⁸⁵ *Ibid*, para 9.

¹⁸⁶ *Ibid*, para 7.

¹⁸⁷ *Constitution of the World Health Organization*, signed 22 July 1946, 14 UNTS 185, preamble (entered into force 7 April 1948).

¹⁸⁸ D.C. Wertz, J.C. Fletcher and K. Berg, *Review of Ethical Issues in Medical Genetics* (2003), [88], WHO Doc WHO/HGN/ETH/00.4.

¹⁸⁹ *WHO-Report*, above n 43, 6.

itself to the advancement of the right to health in international law¹⁹⁰ is far from associating germ-line interventions with this right. All aspects considered, it certainly remains a radical idea to include germ-line interventions in the right to health of Article 12 of the ICESCR.

Even if the technology was readily available, supporters of such a radical interpretation of the right to health would face another problem. Since the right only refers to a better health standard, it would be crucial to distinguish between interventions that constitute treatment of diseases and those serving the mere enhancement of the individual. This distinction is particularly relevant since objections against the treatment of diseases are mainly based on the biological risks for future generations, whereas the enhancement of human traits meets with the fundamental moral criticism that we do not have the right to predetermine the characteristics of future individuals and impose our conceptions of good and bad on them.¹⁹¹ Both in the legal and the moral sphere, the distinction remains very complicated since there is no universally acknowledged concept of disease.¹⁹² Should we make a difference between a child with a prospect of reaching a height of 1.60 meters because of his parents' shortness and a child with the same prospect, whose parents are tall but who suffers from a growth hormone deficiency? Considering that one can hardly claim that the human immune system does not work properly without vaccinations, is the common vaccination against flu a preventive treatment or an enhancement? Since the dividing line blurs in practice groups with different norms and values would probably decide those borderline cases differently.¹⁹³ Of course, just because the distinction is difficult and enhancements are morally questionable, it does not mean that necessarily all germ-line interventions should be prohibited. However, the slippery slope from therapeutic interventions to interventions motivated by vanity remains one of the major objections against all kinds of direct germ-line interventions.

In the light of the above, it is questionable if the right to health stands in the way of prohibitions of germ-line interventions. This is also true for the rights of the child, which I had already identified as possible supporters of such genetic interferences. However, we can say that once those interventions are reasonably safe and their benefits clearly outweigh their risks, a new assessment will be required. For the time being, we have to content ourselves with this result since any anticipated judgment would have to be highly speculative. A lot

¹⁹⁰ World Health Organization, *Health and Human Rights*, World Health Organization <<http://www.who.int/hhr/en/>> at 21 October 2007.

¹⁹¹ Roberto Andorno, 'Biomedicine and International Human Rights Law: In Search for a Global Consensus' (2002) 80(12) *Bulletin of the World Health Organization* 959, 961.

¹⁹² Wilkie, above n 44, 136; Edgar and Tursz, above n 37, 2.

¹⁹³ Buchanan et al, above n 3, 119+151.

depends on the scientific progress, which we will turn to now in the context of the human rights to benefit from scientific progress and the freedom of scientific research.

(5) The Right to Benefit from Scientific Progress and the Freedom of Scientific Research

Article 27(1) of the UDHR contains the freedom of scientific research and the individual's right to enjoy the benefits thereof. This right is also laid down in article 15(1)(b) of the ICESCR. The freedom of scientific research ranks so high among the rights and freedoms in international law that the discussion deals more with limitations of academic liberties rather than the struggle to implement them. During the discussions on the UDHR in the third committee of the UN General Assembly, delegates expressed their opinion that democracy and politics should serve science rather than vice versa.¹⁹⁴ About half a decade later, the explanatory report on the European Convention on Human Rights and Biomedicine confirmed that

[f]reedom of scientific research in the field of biology and medicine is justified not only by humanity's right to knowledge but also by the considerable progress its results may bring in terms of the health and well-being of persons.¹⁹⁵

Its companion, the right of everyone to enjoy the benefits of scientific progress and its applications, appears to have an 'enormous potential for further development in law and society.'¹⁹⁶ At the same time, it has not been explored much since other rights usually cover the progress once it has become standard.¹⁹⁷ The enjoyment of benefits is achieved through the retrieval of information about progress as much as through the access to the relevant applications.¹⁹⁸ The access to germ-line interventions surely falls into the scope of the right, since scientific progress particularly includes natural and biological sciences.¹⁹⁹ In the context of medicine, it was said that

¹⁹⁴ Ragnar Adalsteinsson and Páll Thórhallson, 'Article 27' in Gudmundur Alfredsson and Asbjørn Eide (eds) *The Universal Declaration of Human Rights* (1999) 575, 578.

¹⁹⁵ *Convention on Human Rights and Biomedicine, Explanatory Report*, above n 25, para 95.

¹⁹⁶ Adalsteinsson and Thórhallson, above n 194, 593.

¹⁹⁷ *Ibid* 575.

¹⁹⁸ Asbjørn Eide, 'Cultural Rights as Individual Human Rights' in Asbjørn Eide, Catarina Krause and Allan Rosas (eds) *Economic, Social and Cultural Rights* (2001) 289, 295.

¹⁹⁹ *Ibid*.

[w]hen significant new treatments are discovered which make it possible to cure diseases which were in the past incurable, the state must be considered obliged, within the limits of its available resources, to make that treatment available.²⁰⁰

Despite these statements in favour of the freedom of scientific research and the individual's right to enjoy its benefits, research is not unbridled. The UN General Assembly noted in 1975 that 'scientific and technological progress has become one of the most important factors in the development of human society' but that it can also 'give rise to social problems, as well as threaten the human rights and fundamental freedoms of the individual.'²⁰¹ As for the freedom of scientific research States are entitled to prevent the use of scientific and technical progress for purposes contrary to the enjoyment of other human rights.²⁰² UNESCO's Universal Declaration on the Human Genome and Human Rights reflects the drafters' understanding that research is a fundamental aspect of humanity and restrictions have to be interpreted narrowly. They can only be justified through the human rights, fundamental freedoms and human dignity of other individuals, as well as the protection of public health.²⁰³ Article 4 of the ICESCR, for example, explicitly allows for

such limitations as are determined by law only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society.

Hence, both the freedom of scientific research and the individual's right to enjoy the benefits thereof are subject to their compatibility with other human rights, fundamental freedoms and human dignity.

In conclusion, the freedom of scientific research and the right to enjoy the benefits thereof *prima facie* cover the research on germ-line interventions and their later application. Research is necessary to make the genetic procedures safe. Once this is achieved, people could have a right to benefit from them. This is particularly the case if one stresses the

²⁰⁰ Ibid 296.

²⁰¹ *UN Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind*, GA Res 3384 (XXX), UN GAOR, 30th sess, 2400th plen mtg, preamble, UN Doc A/RES/3384 (1975).

²⁰² *Revised general guidelines regarding the form and contents of reports to be submitted by States parties under articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights*, Committee on Economic, Social and Cultural Rights, [20] UN Doc E/C.12/1991/1 (1991).

²⁰³ *Universal Declaration on the Human Genome and Human Rights*, above n 14, arts 10, 12(a), 15; see also *Convention on Human Rights and Biomedicine, Explanatory Report*, above n 25, para 96, and the *Report on the 5th session, 26 November-14 December 1990*, Committee on Economic, Social and Cultural Rights, [88-110], UN Doc E/1991/23 (1990).

beneficial aspects of therapeutic germ-line interventions and ignores the potential risks. Nonetheless, the uncertainty about long-term effects and the moral uneasiness caused by the interference with another individual's genetic dispositions remain. As mentioned above, those objections could be expressed on the basis of human dignity and the human rights and fundamental freedoms of others. Before I turn to the question of whether those rights demand a prohibition of germ-line interventions and limit the freedom of research and its application, I will shortly sum up the results of the analysis so far.

(6) Conclusion

Apparently, there are no convincing ways to support a parents' or child's right to germ-line interventions unless one chooses a very radical interpretation of the according provisions. Although there is a noticeable tendency among philosophers and medics to stress the beneficial sides of eugenics and the moral obligation to spare future generations the scourge of severe diseases such an obligation does not have a legal counterpart. Of course, since widespread germ-line interventions are still dreams of the future, there was no real chance for international law to develop rights that explicitly promote them. Nevertheless, the realms of ethics and law alike support the enquiring mind and scientific curiosity. It is for this reason that I have argued that the freedom of scientific research and the human right to benefit from its applications support the research on beneficial uses of germ-line interventions. Since little is known about their actual consequences, more research would be necessary to be able to achieve an accurate risk-benefit ratio. Conversely, international law that deals with biomedicine and anticipates scientific development tends to be restrictive rather than permissive. This is not only the case with the texts on germ-line interventions but can also be seen in the case of reproductive cloning. The European Anti-Cloning Protocol, for example, prohibits reproductive cloning and justifies the prohibition with the supposed violation of human dignity and the 'serious difficulties of a medical, psychological and social nature that such a deliberate biomedical practice might imply for all the individuals involved.'²⁰⁴ On the global level, however, a binding prohibition of reproductive cloning is hindered by 'uncertainty over new scientific advances, as well as its ethical, cultural and religious implications.'²⁰⁵ The uneasiness expressed in the Universal Declaration on the Human

²⁰⁴ *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*, opened for signature 12 January 1998, ETS No 168, preamble (entered into force 1 March 2001) ('*Anti-Cloning Protocol*').

²⁰⁵ *General Assembly adopts United Nations Declaration on Human Cloning by Vote of 84-34-37*, United Nations Press Release of 8 March 2005, UN Doc GA/10333 (2005).

Genome and Human Rights and, in contrast to that, the explicit prohibition of germ-line interventions in the European Convention on Human Rights and Biomedicine also reflect this discrepancy between regional and global arrangements. The paper will now attempt to determine whether there are aspects of international law that conclusively stipulate the prohibition of germ-line interventions and thereby limit the freedom of scientific research and the right to enjoy the benefits thereof.

Genome Interventions and Restrictive International Law

Despite all prophecies of doom, the aim of a better, healthier life for every human being is unexceptionable. A ubiquitous human genetic modification practice will not necessarily result in the dystopian scenarios often envisaged. Public policy could avoid errors and abuses associated with the past eugenics and harness genetic powers to help create a more just and humane, particularly healthy society.²⁰⁶ In contrast, critics might say that despite the positive effects on human health genetic modification puts humankind on a slippery slope to an objectification of human beings who would be used as objects for secondary goals.²⁰⁷ It would be a short trip from preventing Down's syndrome to preventing the birth of boys or girls (whichever seems more socially desirable), or from preventing children with genetic defects to children who lack intelligence, beauty or simply chances for success.²⁰⁸ Once the technology is available, social and economic pressure might urge parents to make use of it and might marginalize sexually perceived children. In the same vein, the IBC's Report on Human Gene Therapy of 1994 stated that to direct evolution by choosing the traits and heightening the capacities of future generations 'would violate fundamental rights of individuals so constructed.'²⁰⁹ However, the report is silent on the specific rights, a flaw I will try to iron out in the following pages.

(1) Human Dignity

Opponents of genetics and genomics tend to field human dignity as a rhetoric all-purpose tool against techniques they intuitively dislike.²¹⁰ Human dignity is one of the few common values

²⁰⁶ *WHO-Report*, above n 43, 162-5; Buchanan et al, above n 3, 22.

²⁰⁷ Gebhart Fürst, 'The (Im)perfect Human – His Own Creator? – Bioethics and Genetics at the Beginning of Life' in Christoph W. Sensen (ed) *Handbook of Genome Research* (2005) vol.2, 561, 563.

²⁰⁸ Buchanan et al, above n 3, 2-4.

²⁰⁹ Edgar and Tursz, above n 37, 2.

²¹⁰ Deryck Beyleveld and Roger Brownsword, 'Human Dignity, Human Rights, and Human Genetics' (1998) 61 *Modern Law Review* 661, 680; Dieter Birnbacher, 'Do Modern Reproductive Technologies Violate Human Dignity' in Elisabeth Hildt and Dietmar Mieth (eds) *In Vitro Fertilisation on the 1990s, Towards a Medical, Social and Ethical Evaluation* (1998) 325, 326.

in the world.²¹¹ However, we buy this unity with the extreme nebulousness of the concept. While the notion of human dignity appears in the Charter of the United Nations,²¹² the UDHR,²¹³ the ICESCR and ICCPR²¹⁴ and several other human rights treaties, no one has ever clearly defined it. Its interpretations vary considerably in different national and cultural backgrounds,²¹⁵ and the endless discussions among philosophers over the last centuries fill books and libraries. It is, of course, not surprising that something so essential but yet as nebulous as human dignity eludes a universal definition. Therefore, the concept of human dignity is seldom able to provide concrete solutions on its own but, characterised as the backbone of human rights rather than being a human right itself,²¹⁶ operates through concrete notions of specific human rights.²¹⁷ For example, human dignity might help interpreting human rights in cases of ambiguity and tip the scales in cases where positive law reaches its limits. Its vagueness is curse and blessing at the same time. While it provides room for ethical discussions that are beyond the plain words of human rights treaties, commentators can also use it for their purposes and interpret it according to their own personal morals. As mentioned above, opponents of genomics invoke human dignity as a key objection against germ-line interventions. However, the following discussion will reveal that this is an arguable point of view. The first question is whether human dignity can theoretically collide with germ-line interventions at all. The second question is whether human dignity actually prohibits germ-line interventions. Since the legal discussion on the notion of human dignity has a tendency to turn into a discussion on metaphysics and natural law, I will start with a brief insight into the philosophical discussion.

It is widely recognized that human dignity is best defined negatively. Rather than giving a positive outline of the scope of the concept scholars prefer to identify the acts that violate human dignity. Over decades, various definitions have gained recognition, two of the most predominant I want to present here. German philosopher Immanuel Kant regarded violations of human dignity as the treatment of people only as a means and not as an end themselves.²¹⁸ In the Kantian view, either things have a price and can be replaced by an

²¹¹ Herbert Spiegelberg, *Steppingstones Toward an Ethics for Fellow Existents. Essays 1944-1983* (1986) 198.

²¹² *Charter of the United Nations*, opened for signature 26 June 1945, 14 UNTS xvi, preamble (entered into force 24 October 1945).

²¹³ *Universal Declaration of Human Rights*, above n 13, preamble and art 1.

²¹⁴ *International Covenant of Economic, Social and Cultural Rights*, adopted by UNGA Res 2200(XXI) (1966), 993 UNTS 3, preamble (entered into force 3 January 1976); *International Covenant of Civil and Political Rights*, adopted by UNGA Res 2200(XXI) (1966), 999 UNTS 171, preamble (entered into force 23 March 1976).

²¹⁵ Bartha M. Knoppers, *Human Dignity and Genetic Heritage* (1991) 24.

²¹⁶ Knoppers, *ibid*; Lenoir, above n 17, 562.

²¹⁷ Andorno, above n 191, 960.

²¹⁸ Immanuel Kant, *The Metaphysics of Morals* (Mary Gregor trans, 1996 ed) 209 [trans of: *Metaphysik der Sitten*].

equivalent, i.e. a mean that serves the same purpose, or they have a dignity, which makes them beyond price.²¹⁹ Most of today's definitions reflect the Kantian view and describe violations of human dignity as the treatment of a human being as a legal object of the will of others.²²⁰ In legal practice, this results in the priority of a person's individual choices and the requirement of compelling reasons for interferences and means of coercion. Thus, States may not 'extend their authority into areas of human life that are essentially personal and familial.'²²¹

However, it is one thing to invoke human dignity in order to repel a State's interference with personal matters. In the context of genomics, this would result in, for example, the protection of humans against a State's coercive eugenic measures. As elaborated earlier, the drafters of the European Convention on Human Rights and Biomedicine and the Universal Declaration on the Human Genome and Human Rights have chosen this approach.²²² In contrast, it is quite another thing to protect someone's human dignity against violations deliberately and consciously caused by that same someone. The somewhat paradoxical result would be that human dignity would conflict with human autonomy and self-determination – which form part of the concept of human dignity themselves. As a consequence, human dignity would lend itself to both sides of the argument. Kant tells us that in those cases human autonomy has to give way to dignity. Human beings could not sell themselves for a price without violating their duty of self-esteem.²²³ Others, following a rights- rather than Kant's duty-led perspective, regard this limitation of free choice as 'misguided paternalism.'²²⁴ In connection with germ-line interventions the conflict between those opposing views is insignificant. Parents would not waive their own but their future offspring's dignity. Here, we once again meet with the problem of rights of future generations. Considering that the UDHR merely acknowledges that '[a]ll human beings are *born* free and equal in dignity and rights,'²²⁵ it is doubtful whether human dignity applies to generations not yet conceived. Kant's so-called 'kingdom of ends,' for example, 'is possible only through the autonomy, or the freedom of will, of its members. This autonomy is the ground of their absolute value, their "dignity".'²²⁶ This implies that it requires living individuals with the competence to will. By the same token, supporters of the rights-led

²¹⁹ Herbert J. Paton, *The Moral Law : Kant's Groundwork of the Metaphysic of Morals* (1948) 189.

²²⁰ Marks, above n 11, 120; Otto Schachter, 'Human Dignity as a Normative Concept' (1983) 77 *American Journal of International Law* 848, 849; but see Beyleveld and Brownsword, above n 210.

²²¹ Schachter, above n 220, 850.

²²² See above p 2f.

²²³ Kant, above n 218.

²²⁴ Beyleveld and Brownsword, above n 210, 680.

²²⁵ *Universal Declaration of Human Rights*, above n 13, art 1 (emphasis added).

²²⁶ Paton, above n 219, 189.

approach admit that until they know if the offspring with a manipulated genome ‘might be regarded as inferior, leading to them valuing themselves less than those whose genome has not been so manipulated’ they are not sure whether human dignity is at stake at all.²²⁷ Consequently, they can only ‘place a question mark against the treatment of potential agents.’²²⁸ In conclusion, both approaches do not provide the means to let human dignity transcend generations. As opposed to the understanding that dignity derives from human rationality, others argue that human dignity simply derives from our belonging to the human species. Yet again, under this theory, it is only ‘straightforward to ascribe full rights to those who are conceived but not born,’²²⁹ but it does not give a satisfactory answer to the question of the human dignity of the not yet conceived. However, even though those theories do not necessarily support such an idea, this is not to say that a generic, abstract concept of human dignity is unthinkable.²³⁰

Noting that those philosophical approaches do not necessarily envisage the human dignity of generations not yet conceived, it is interesting to see how international law deals with that problem. The question is whether there is a metaphysical or natural law common to a timeless humanity as a whole that cannot be waived by anyone at anytime. Germ-line interventions can only violate human dignity if one answers this question in the affirmative. In 1975, the UN Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind²³¹ stated that scientific and technological achievements could be used to the detriment of human rights and fundamental freedoms and the dignity of the human person. For the realm of genetics, the explanatory report on the 1997 European Convention on Human Rights and Biomedicine acknowledged the problems biomedicine might pose not only to individuals and society but also to the human species itself.²³² The drafters therefore included safeguards in the preamble, referring to the benefits to future generations and humanity as a whole²³³ – present and future. Conversely, the report makes clear that the convention is based on the ‘generally accepted principle that human

²²⁷ Beyleveld and Brownsword, above n 210, 678.

²²⁸ Ibid.

²²⁹ Déirdre Dwyer, ‘Beyond Autonomy: The Role of Dignity in “Biolaw”’ (2003) 23(2) *Oxford Journal of Legal Studies* 319, 321.

²³⁰ See especially Roberto Andorno, *Human Dignity and the UNESCO Declaration on the Human Genome* (2003) [7] Cardiff Centre for Ethics, Law and Society <<http://www.ccels.cf.ac.uk/archives/publications/2003/andornopaper.pdf>> at 21 October 2007; Birnbacher, above n 210, 330.

²³¹ *UN Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind*, GA Res 3384 (XXX), UN GAOR, 30th sess, 2400th plen mtg, UN Doc A/RES/3384 (1975) art 8.

²³² *Convention on Human Rights and Biomedicine, Explanatory Report*, above n 25, para 14.

²³³ Ibid.

dignity and the identity of the human being had to be respected *as soon as life began*.²³⁴ Hence, it would have been contradictory if the report had used human dignity as a basis for the prohibition of germ-line interventions in Article 13 of the convention. As noted earlier, the report does not give any reasons for the prohibition at all. We can only assume that the drafters were simply more afraid of the possible misuses of germ-line interventions than thrilled by the possible benefits, without further reference to legal justifications.

In contrast, other legal texts strongly support the argument for the recognition of human dignity of future generations. The Universal Declaration on the Human Genome and Human Rights reserves its first four articles to '[h]uman dignity and the human genome.'²³⁵ The idea of a dateless concept of human dignity shines through the statement that the genome underlies 'the fundamental unity of all members of the human family' and that it, '[i]n a symbolic sense, [...] is the heritage of humanity.'²³⁶ Moreover, Article 24 of the declaration implies that future generations too can be protected by the concept of human dignity since it denominates germ-line interventions as a practice that could be contrary to human dignity. Unless the drafters thought that human dignity was generally capable to transcend to future generations, such a provision would be pointless. We find a similar situation in the provisions on human cloning. The Council of Europe's 1998 Anti-Cloning Protocol states that 'the instrumentalisation of human beings through the deliberate creation of genetically identical human beings is contrary to human dignity.'²³⁷ The explanatory report clarifies that the protocol outlaws 'the instrumentalisation of artificially cloned human offspring'²³⁸ and thereby acknowledges that these non-existent clones can be protected by human dignity. Of course, considering that the UN Charter and the UDHR understand human dignity as belonging to humanity consisting of *born* human persons,²³⁹ this approach by the European Anti-Cloning Protocol must be regarded as a novelty in international law. However, only this understanding makes the invocation of the concept of human dignity against germ-line interventions possible. It is practically not important whether and how such an approach is feasible under metaphysics and natural law. What counts for the matters of this paper is that the drafters of the above provisions believed that it was. At the same time, they raised the

²³⁴ Ibid, para 19 (emphasis added).

²³⁵ *Universal Declaration on the Human Genome and Human Rights*, above n 14, title of part A.

²³⁶ Ibid, art 1.

²³⁷ *Anti-Cloning Protocol*, opened for signature 12 January 1998, ETS No 168, preamble (entered into force 1 March 2001).

²³⁸ *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, Explanatory Report* (1998) [3] Council of Europe <<http://conventions.coe.int/Treaty/en/Reports/Html/168.htm>> at 21 October 2007.

²³⁹ *Charter of the United Nations*, opened for signature 26 June 1945, 14 UNTS xvi, preamble (entered into force 24 October 1945); *Universal Declaration of Human Rights*, above n 13, art 1.

question if germ-line interventions actually violated human dignity,²⁴⁰ which we will turn to now.

When it comes to genetics, the vagueness of the concept of human dignity is accompanied by, what professor of philosophy Kurt Bayertz called, a ‘great uneasiness.’²⁴¹ The same uneasiness is omnipresent in the discussion on present technologies like *in vitro* fertilization and prenatal diagnostics or surrogacy. The key objection against germ-line interventions is that they bring human beings into the realm of designed items subject to the fashions of the times²⁴² or, as a UNESCO report put it, that germ-line interventions would be close to baking a cake.²⁴³ Noticeably, this vocabulary is in line with the definitions of violations of human dignity as the treatment of humans as objects. For this reason, one commentator goes so far as to demand that germ-line interventions should be declared crimes against humanity.²⁴⁴ On the other side of the spectrum, biologists like Richard Dawkins stated that humans are nothing but ‘survival machines – robot vehicles blindly programmed to preserve the selfish molecules known as genes.’²⁴⁵ Others agree by saying that ‘[a] person is only a gene’s way of making another person.’²⁴⁶ Furthermore, it is argued that the natural gene pool never was static and never will be, since we have changed and evolved over time being in a state of constant mutation.²⁴⁷ As to the relationship of human beings to their genes, Dawkins also stated that

[t]he individual organism came first in the biologist’s consciousness, while the replicators – now known as genes – were seen as part of the machinery used by individual organisms. It requires a deliberate mental effort to turn biology the right way up again, and remind ourselves that the replicators came first, in importance as well as in history.²⁴⁸

²⁴⁰ *Universal Declaration on the Human Genome and Human Rights*, above n 14, art 24.

²⁴¹ Kurt Bayertz, *GenEthics* (Sarah L. Kirkby trans, first published 1987, 1994 ed) 77, 82 [trans of: *GenEthik*].

²⁴² Council for Responsible Genetics, above n 37; Galjaard, above n 35, para 98.

²⁴³ Edgar and Tursz, above n 37, 14.

²⁴⁴ Annas, above n 56.

²⁴⁵ Richard Dawkins, *The Selfish Gene* (2nd ed, 1979) v.

²⁴⁶ Melvin Konner, as cited in Sheila Greene ‘What Makes a Person a Person? The Limits and Limitations of Genetics’ in Maureen Junker-Kenny (ed) *Designing Life? Genetics, Procreation and Ethics* (1999) 79, 81.

²⁴⁷ Bartha M. Knoppers, ‘International Arbitrage of Controversial Medical Technologies: Human Dignity: In Danger of Banality? (The Case of Cloning)’ (2003) 35 *Case Western Reserve Journal of International Law* 385, 393.

²⁴⁸ Dawkins, above n 245, 265.

From that point of view, the development within the field of gene technology is “revolutionary” only with regard to its *means* and not with regard to its effects.²⁴⁹ However, for the Enquete Commission of the German *Bundestag* those revolutionary means violate human dignity. The commission stated that human dignity implies that humans are a product of chance, which secures the independence of human beings from each other.²⁵⁰ Unfortunately, it does not explain any further why human beings must be a product of chance. In contrast to Dawkins’ idea of the “selfish gene”, the underlying concept of the Universal Declaration on the Human Genome and Human Rights is that ‘human beings cannot be reduced to the sum of their genes’ at all.²⁵¹ It is argued that since we share 99 per cent of our DNA with chimpanzees, our humanness must have a spiritual rather than a material dimension.²⁵² This means that interference with the genetic material does not violate human dignity because of the effects on the genome itself but because of the consequences for the self-understanding of humans. From this brief insight into the discussion, it is obvious that neither biologists nor international lawyers nor philosophers can provide a definitive answer, which is not surprising with regard to our pluralistic society and the broad scope of possible foundations and interpretations of human dignity. Hence, in the aftermath of the publication of the Enquete Commission’s report, German philosopher Hans-Martin Sass argued that ‘[t]he issue is not whether or not human dignity allows germ-line manipulation, but which forms of germ-line manipulations [...] are morally acceptable and which are not.’²⁵³ According to Sass, only a public debate and discussions among professional organisations, regulators and legislators can give answers to those questions which could not ‘be predetermined by [...] referring to obscure natural law concepts.’²⁵⁴ I find it reasonable to assume that the concept of human dignity cannot answer the question of the permissibility of germ-line interventions unless the international community or single nations decide that it should or should not. Even at the end of such a debate, results can never be certain since the pluralistic moral world defies simplified heuristics. This is particularly true when this moral world shall come into effect through rigid legal terms.

Some States will probably argue that any kind of direct germ-line intervention makes children the object of their parents’ personal, cultural or aesthetic desires and therefore

²⁴⁹ Bayertz, above n 241, 22.

²⁵⁰ Enquete Commission to the Bundestag of the Federal Republic of Germany, ‘Prospects and Risks of Gene Technology’ (1988) 2(3) *Bioethics* 254, 257.

²⁵¹ Lenoir, above n 17, 566.

²⁵² Roberto Andorno, above n 230, 4.

²⁵³ See especially Hans-Martin Sass, ‘A Critique of the Enquete Commission’s Report on Gene Technology’ (1988) 2(3) *Bioethics* 264, 269.

²⁵⁴ *Ibid* 272.

violates human dignity. Others could argue that, granted that it can be done safely, at least the treatment of severe diseases has nothing to do with parental idiosyncrasies and is a moral obligation towards future generations. Sceptics would then bring forward that once some germ-line interventions are permitted the term “disease” might be interpreted more and more widely. The intellectual quandary is that questions of procreation are a typical case of parental autonomy while the consequences of germ-line interventions might considerably affect societies and humanity as a whole. Both, parents who shape their children without limits and States that over-patronise their citizens leave a bitter aftertaste in the context of human dignity. So does the prospect of better lives for future generations compared to the risk for those generations of unforeseen, detrimental late-effects of germ-line interventions. Therefore, in my opinion, the debate on the violation of human dignity by germ-line interventions must result in an insoluble stalemate. This is not to say, however, that international law will not be able to find a definitive answer in terms of the international community’s smallest common denominator. So far, different assessments of the risk-benefit ratio have led to absolute prohibitions on the one side²⁵⁵ and the opposition against non-therapeutic germ-line interventions on the other side.²⁵⁶ Instead of the vague concept of human dignity, these kinds of assessments should determine the future of germ-line interventions. However, this excursion to human dignity will turn out to be helpful for our analysis of other possible rights opposing germ-line interventions.

(2) The Rights of Others and Duties to Society

Article 29 of the UDHR makes it clear that human rights are the flipside of duties to society and are limited by ‘the rights and freedoms of others’ as well as ‘just requirements of morality, public order and the general welfare in a democratic society.’²⁵⁷ It is unquestionable that ‘[s]ociety has good, if not conclusive, reason to restrict liberties of individuals if the exercise of these liberties undermines a public good.’²⁵⁸ The determination of a child’s sex serves as a very illustrative example for that. In some cultures it is still of great advantage to be male. However, if everyone became male, this would be a self-defeating development and pose dangers to the social and biological structure.²⁵⁹ The question is what rights could be invoked to protect future generations. I have already discussed that the idea of enforceable,

²⁵⁵ *Convention on Human Rights and Biomedicine*, above n 15, art 13.

²⁵⁶ Edgar and Tursz, above n 37, 17; Sturges, above n 9, 258; *WHO-Report*, above n 43, 113.

²⁵⁷ *Universal Declaration of Human Rights*, above n 13, art 29(2).

²⁵⁸ Buchanan et al, above n 3, 183+205.

²⁵⁹ Ibid 183. For the possible consequences of a society with too few women see e.g. Margaret Atwood’s novel *A Handmaid’s Tale* (1985).

legal rights of future generations is not yet established.²⁶⁰ Nonetheless, a great number of splendid sounding rights circulate on the parquet of international law. Among them are the right of future generations to be free of genetic alterations made without their consent,²⁶¹ the right of future generations not to be experimented upon,²⁶² the child's right to an untouched genetic inheritance²⁶³ or to being unplanned,²⁶⁴ or the collective human right to live in a world that is genetically diverse.²⁶⁵ However, they seem to be more of a moral rather than a legal nature. Bayertz notes that '[a]ll of these rights are the direct or indirect expression of certain values and ideas in life,'²⁶⁶ and, indeed, they seem to reflect more what some commentators think *should be* rather than what *is*. Attempts to establish such rights date back to as early as 1982. Back then, the Parliamentary Assembly of the Council of Europe stated in its Recommendation 934 on genetic engineering that 'Articles 2 and 3 of the European Convention on Human Rights imply the right to inherit a genetic pattern which has not been artificially changed.'²⁶⁷ Such a right benefits future generations and covers children who are not yet conceived. Despite the very definitive tone this specific recommendation has two flaws. First, it is not absolute. Only two paragraphs later, the Assembly recommends that

the recognition of this right must not impede development of the therapeutic applications of genetic engineering (gene therapy), which holds great promise for the treatment and eradication of certain diseases which are genetically transmitted.²⁶⁸

Hence, artificial changes are permitted for the purpose of gene therapy, which itself is not defined in the recommendation and therefore leaves room for broad interpretations. For this reason, the drafters envisaged but never implemented a list of illnesses to be permissible for gene therapy.²⁶⁹ Nevertheless, the fact that the Assembly did not dare to claim such a right without providing for the exception of therapeutic interventions makes it difficult to argue that there is an absolute right to an untouched genome. Second, it speaks volumes that more than 20 years after the Assembly's suggestion to lay down such a right explicit in the European

²⁶⁰ See above p 2.

²⁶¹ Margaret Somerville, above n 6, 873.

²⁶² Edgar and Tursz, above n 37, 16.

²⁶³ W. French Anderson, above n 7, 665.

²⁶⁴ Bayertz, above n 241, 257.

²⁶⁵ Munayyer, above n 8, 717.

²⁶⁶ Bayertz, above n 241, 259.

²⁶⁷ *Recommendation 934 (1982) on genetic engineering*, Council of Europe, Parliamentary Assembly, 33rd sess, part III, 22nd sitting, Texts adopted, para 4(a).

²⁶⁸ *Recommendation 934 (1982) on genetic engineering*, above n 267, para 4(c).

²⁶⁹ See Knoppers, above n 215, 28.

Convention on Human Rights,²⁷⁰ such an amendment has not taken place. Furthermore, a lot of international lawyers regard such a right as a mixed blessing. The members of the IBC's working group on human gene therapy, for example, expressed their view that 'to invoke a child's right to an unaltered genetic makeup so as to visit upon him conditions incompatible with prolonged life is too paradoxical to be accepted.'²⁷¹ In conclusion, the recognition of any of the above rights seems to be premature and does not reflect the current state of international human rights law.

(3) The Prohibition of Germ-line Interventions for Non-Therapeutic Purposes – An Evolving Customary Rule

Turning away from the mere human rights perspective, I want to argue that there is a general international rule evolving that prohibits germ-line interventions for non-therapeutic purposes. The first example would be the absolute ban in the European Convention on Human Rights and Biomedicine of interventions aimed to introduce any modification in the genome of any descendants.²⁷² Admittedly, with only 21 ratifications after almost eight years, the importance of this provision is questionable. It would also be difficult to argue that there is an international consensus on *absolute* prohibitions considering that during the drafting of the Universal Declaration on the Genome and Human Rights members of UNESCO rejected the German suggestion to amend such an absolute prohibition of germ-line interventions.²⁷³ Nonetheless, there is a broad consensus that, unlike interventions to prevent severe hereditary diseases, non-therapeutic germ-line interventions are not permissible.²⁷⁴ This reasoning was predominant in the Parliamentary Assembly of the Council of Europe in 1982²⁷⁵ and is still upheld by UNESCO and WHO.²⁷⁶ As the verdict goes, 'future individuals [...] should be free to develop their potentialities without being biologically conditioned by the particular conceptions of "good" and "bad" human traits that were dominant at the time they were conceived.'²⁷⁷ Even liberal supporters of germ-line interventions admit that 'knowing that something is an enhancement should [...] raise a moral warning flag' particularly because the question of 'whether some enhancements constitute benefits will depend on the values

²⁷⁰ *Convention for the Protection of Human Rights and Fundamental Freedoms*, opened for signature 4 November 1950, ETS No 5 (entered into force 3 September 1950).

²⁷¹ Edgar and Tursz, above n 37, 17.

²⁷² *Convention on Human Rights and Biomedicine*, opened for signature 4 April 1997, ETS No 164, art 13 (entered into force 1 December 1999).

²⁷³ Lenoir, above n 17, 555-6.

²⁷⁴ Edgar and Tursz, above n 37, 2.

²⁷⁵ *Recommendation 934 (1982) on genetic engineering*, above n 267, para 4(c).

²⁷⁶ Edgar and Tursz, above n 37, 17; *WHO-Report*, above n 43, 113

²⁷⁷ Galjaard, above n 35, para 97.

individuals hold, and parents' values may not always coincide with those of their offspring.²⁷⁸ Although parents have considerable influence on their children once they are conceived or born, children can express their own views which must be given due weight in accordance with their age and maturity and which can be legally enforced.²⁷⁹ Conversely, a child who does not want to be a basketball player but a jockey would meet difficulties to fulfil this dream if his or her parents had decided to have their offspring's height increased to 2.20 meters to provide him with the best chances for a career in basketball. While with a natural height of 2.20 meters children would have no one to blame, they might feel like the mere instrument of their parent's wishes if they are genetically "enhanced" to that height. With regard to the unanimous condemnation of germ-line interventions for non-therapeutic purposes in the international community, the result of this analysis is that there is a rule of customary law evolving that unequivocally prohibits germ-line interventions that aim for the enhancement of offspring's traits. In this case, human dignity might tip the scales for such a prohibition since one could certainly argue that enhancements will usually make the child a defenceless object of the parent's plan for his or her future, no matter if they are well-intended or not.

While the prevention of diseases and disabilities is less controversial, it also meets with criticism. Those who fear that therapeutic germ-line interventions will question the worth of disabled people and foster social discrimination on genetic grounds oppose even the prevention of diseases through genomics.²⁸⁰ Disabled or diseased persons would have to fear that the widespread prevention of disabilities fosters the discrimination against them. Thereby, genomics could unwittingly marginalize individuals with apparent hereditary disabilities who cannot afford to enhance their genome. From this point of view, we should not change individuals to fit society but change society to accommodate individuals. Questions of discrimination and the rights of the disabled also form a considerable part of Iulia-Antoanella Motoc's report on human rights and bioethics to the UN Commission on Human Rights.²⁸¹ The basis for the connection of therapeutic germ-line interventions and discrimination and rights of disabled is the principle of equality, which states that differential treatment due to special features of a person or group of people violates a fundamental principle of human

²⁷⁸ Buchanan et al, above n 3, 154.

²⁷⁹ *Convention on the Rights of the Child*, adopted by UNGA Res 44/25 (1989), 1577 UNTS 3, art 12 (entered into force 2 September 1990).

²⁸⁰ See the passage on the radical disabilities rights advocates' complaints in Buchanan et al, above n 3, 264-6.

²⁸¹ Motoc, above n 5, paras 34-44.

rights law.²⁸² Since non-discrimination clauses usually relate to the rights laid down in the according codification and do not form a general prohibition of discrimination,²⁸³ UNESCO and the Council of Europe incorporated special provisions in their respective texts. They prohibit the discrimination on genetic grounds²⁸⁴ and require the confident handling of genetic data²⁸⁵ in order to nip genetic discrimination in the bud.

In response to the above concerns, one can say that germ-line interventions do not question that disabled persons are as worth as persons without disabilities. Preventing a serious disease or disability is directed at the disadvantage and the suffering they can cause, not at existing persons with the disease or disability.²⁸⁶ The prevention of disabilities also creates great opportunities for the integration of people who would have been disabled, but benefited from germ-line interventions. This must and should not mean that the integration of the remaining disabled people comes to a halt. Legally, the principle of equality only requires equal treatment. In the context of the rights of disabled people, this involves that their lives are eased to give them equal opportunities. While they certainly can demand equal treatment, they cannot claim that this equality goes so far as to call for the existence of other disabled people.²⁸⁷ The principle of quality therefore does not entail a prohibition against germ-line interventions. However, it will certainly need to prove its worth when cases of genetic discrimination, particularly in labour and health insurance matters, occur. The mere danger of discrimination, however, does not suffice as a legal argument against therapeutic germ-line interventions. As long as all people are treated equally regardless of their genetic dispositions such a development does not violate human rights, even though genomics undoubtedly add a new ground on the list of reasons for discrimination that human rights law has to be aware of.

²⁸² Sigrun Skogly, 'Article 2' in Gudmundur Alfredsson and Asbjørn Eide (eds) *The Universal Declaration of Human Rights* (1999) 75, 75.

²⁸³ See e.g. the *Universal Declaration of Human Rights*, above n 13, art 2; the *International Covenant of Economic, Social and Cultural Rights*, adopted by UNGA Res 2200(XXI) (1966), 993 UNTS 3, art 2(2) (entered into force 3 January 1976); *Convention on the Rights of the Child*, adopted by UNGA Res 44/25 (1989), 1577 UNTS 3, art 2(1) (entered into force 2 September 1990) and the *Charter of the United Nations*, opened for signature 26 June 1945, 14 UNTS xvi, art 55(c) (entered into force 24 October 1945). An exception is Article 26 of the ICCPR that contains an overall prohibition of discrimination on any ground.

²⁸⁴ *Universal Declaration on the Human Genome and Human Rights*, above n 14, art 6; *Convention on Human Rights and Biomedicine*, opened for signature 4 April 1997, ETS No 164, art 11 (entered into force 1 December 1999).

²⁸⁵ *Universal Declaration on the Human Genome and Human Rights*, *ibid*, art 7; *Convention on Human Rights and Biomedicine*, opened for signature 4 April 1997, ETS No 164, art 10 (entered into force 1 December 1999).

²⁸⁶ Buchanan et al, above n 3, 278.

²⁸⁷ As a diabetic dependent on insulin (type 1), the I can say this from my own experience.

(4) Conclusion

The last pages have shown that in the context of germ-line interventions human dignity cannot be used as a “conversation stopper” (J.F. Keenan) apparently settling an issue once and for all and tolerating no further discussion.²⁸⁸ With the rights of future generations generally standing on shaky legs, it was time for a new provision to develop in international law. In my point of view, the common ground in international law is the prohibition of germ-line interventions for non-therapeutic purposes, notwithstanding the difficulties to distinguish enhancements from treatments. This unambiguous statement would also limit the freedom of research and the rights to benefit thereof on the grounds of biological and social risks too high to allow enhancements, but not high enough to outweigh the benefits of therapeutic germ-line interventions. I admit that research in the direction of therapies will not be separable from research pursuing enhancements. However, the application will be, although borderline cases will always challenge our ethics.

IV. CONCLUSIONS

Humans have long since possessed the tools
for crafting a better world. Where love,
compassion, altruism and justice have failed,
genetic manipulation will not succeed.²⁸⁹

As often in discussion on genetics, there are a lot of questions to ask but only few definitive answers to give. In summary, this article comes to the following results. The analysis of present conventions and declarations dealing with genomics in the second chapter revealed that they form an incoherent picture. What they have in common is the general uneasiness connected with germ-line interventions. However, there is also the prospect of beneficial uses, which presumably prevented the Universal Declaration on the Genome and Human Rights from categorically banning all germ-line interventions. The examination of established human rights in chapter III showed that they deal with genomics rather superficially and cannot provide definitive answers. Procreative liberties, the rights of the child or the right to health have not yet developed enough to establish legal rights to a better living through germ-line interventions. In addition, the problem that the objects of protection of today’s human rights law are exclusively living or at least conceived individuals overshadows all attempts to argue

²⁸⁸ Birnbacher, above n 210, 325.

²⁸⁹ Gina Maranto, *Quest for Perfection: The Drive to Breed Better Human Beings* (1996), 278.

for such rights. However, the well-being of future generations is somewhat reflected in ‘humanity’s right to knowledge [and] the considerable progress its results may bring in terms of the health and well-being of persons,’²⁹⁰ which forms the fundament of the freedom of scientific research and the individual’s right to enjoy the benefits thereof. Those rights could indeed support the research on and later application of germ-line interventions. As opposed to that, genomics are the object of fierce criticism. Some scholars compiled the opposing aspects in a proposal to a convention on the preservation of the human species.²⁹¹ In this draft convention, the prohibition of intentional inheritable modification is based on human dignity, the threat of genetic discrimination, the creation of a subspecies and the danger of eugenic abuses. The Convention would not allow reservations to it and contain strict monitoring and enforcement mechanisms. However, as we have seen, human dignity is not as powerful a weapon against genomics as some might wish, neither is the mere danger of discrimination or references to the abuses of eugenics in the past. Current international law does not contain a conclusive rule against germ-line interventions, unless opponents let their predetermined opinion influence their interpretation of human dignity. However, the unanimous international opposition against the purpose of enhancing human traits could prove to be a customary rule of international law in the near future. While there is a noticeable temptation to accept the risks of germ-line interventions when it comes to severe hereditary diseases, the risk-benefit ratio for mere enhancements is strongly regarded as being in disfavour of germ-line interventions. The more liberal approach to therapeutic germ-line interventions is based on parents’ wide discretion concerning the ways they raise their child and the legal right to speak on his or her behalf. Although they cannot claim to have an enforceable right to have their genome changed, they might be given the freedom to consent to the elimination of a defect gene, if this gene would stand in the way of almost any plan of life that their offspring is reasonably likely to choose. This attitude apparently mirrors the public opinion in the Western world. Surveys show that people tend to disapprove the idea of “designed babies” but feel more comfortable with genetic engineering against hereditary diseases.²⁹² For example, a survey conducted by the Genetic and Public Policy Center among 1,200 adult Americans in October 2002 showed an approval of 59 per cent and disapproval of 34 per cent of

²⁹⁰ *Convention on Human Rights and Biomedicine, Explanatory Report*, above n 25, para 95.

²⁹¹ Annas et al, above n 47, 154-5.

²⁹² Center for Genetics and Society, Public Opinion, *Summary of Survey Results, Inheritable Genetic Modification* (2003) Center for Genetics and Society
<<http://www.genetics-and-society.org/analysis/opinion/summary.html#2>> at 21 October 2007.

respondents asked for their opinion on germ-line interventions to prevent a genetic disease.²⁹³ As for the question of whether parents should change their own genes in order to have children who would be smarter, stronger, or better looking, 20 per cent approved whereas 76 per cent disapproved.²⁹⁴ How a democratically legitimised parliament should deal with a public opinion that favours therapeutic germ-line interventions will certainly concern future politics. Will parliaments rather patronise their citizens for the sake of unaltered but sometimes diseased genomes? Will they allow for artificial tampering with the genome, thereby maybe jeopardizing humanity's gene pool? The questions politicians will have to answer will be: Can future harms – discounted by the probability of their occurrence – really outweigh the benefits of germ-line interventions? On the other hand, can the future generations' hypothesised interest in a disease free existence outweigh the risk for the destruction of the human species through its own hands? If gene therapy was regarded as permissible, the pivotal questions would be what is normal and abnormal, acceptable and unacceptable, viable and non-viable, and even more important: who should decide on those questions? Despite this paper's rather liberal approach towards therapeutic germ-line interventions, we should not forget that sudden alterations of the human gene pool are risky, that even the outcome of beneficial interventions is unknown and that reckless tampering with genes could turn out to be disastrous for humanity. In the end, germ-line interventions should not be undertaken at all until scientists have sufficiently developed the technology to provide a clearly favourable risk-benefit ratio.²⁹⁵ Then again, the necessary experiments themselves will pose questions of human rights and human dignity. In addition, once genetic engineering has become a common procedure, people might be tempted to expand the scope of application more and more. Consequently, biological, psychological and social differences between individuals could be reduced to differences in their DNA and lead to genetic stratification that overestimates the significance of genetic material for a person's abilities. Andrew Niccol's *Gattaca* would have provided a look into our future.

Human rights law cannot answer all those questions but it can determine taboos that must not be broken under any circumstances. According to the present analysis, this taboo is the enhancement of individuals through germ-line interventions, as it is laid down in the attached draft declaration. For the assessment of therapeutic interventions, intensive scientific research is necessary. However, progress should be made with caution. In this regard, I would

²⁹³ Princeton Survey Research Associates for The Genetics and Public Policy Center, *Public Awareness and Attitudes About Genetic Technology, Topline Results* (2002) [25] Genetics and Public Policy Center <<http://www.dnapolicy.org/images/reportpdfs/PublicAwarenessAndAttitudes.pdf>> at 21 October 2007.

²⁹⁴ *Ibid.*, para 24.

²⁹⁵ *WHO-Report*, above n 43, 168.

like to draw a parallel to the precautionary principle established in international environmental law. This principle is applied in the face of environmental hazards and requires preventive and abatement action where serious or irreversible harm is feared, even when uncertainty of whatever nature remains.²⁹⁶ I would therefore like to end this treatise with the same wise words Arie Trouwborst borrowed from ancient philosopher Confucius for the end of his book on the precautionary principle. The cautious seldom err.²⁹⁷

V. APPENDIX

Universal Draft Declaration on the Prohibition of Non-Therapeutic Germ-line Interventions

The General Conference,

Recalling that the Preamble of UNESCO's Constitution refers to 'the democratic principles of the dignity, equality and mutual respect of men', rejects any 'doctrine of the inequality of men and races', stipulates 'that the wide diffusion of culture, and the education of humanity for justice and liberty and peace are indispensable to the dignity of men and constitute a sacred duty which all the nations must fulfil in a spirit of mutual assistance and concern', proclaims that 'peace must be founded upon the intellectual and moral solidarity of mankind', and states that the Organization seeks to advance, 'through the educational and scientific and cultural relations of the peoples of the world, the objectives of international peace and of the common welfare of mankind for which the United Nations Organization was established and which its Charter proclaims',²⁹⁸

Bearing in mind the Universal Declaration of Human Rights proclaimed by the General Assembly of the United Nations on 10 December 1948, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights of 16 December 1966, the United Nations Convention on the Rights of the Child of 20 November 1989, the United Nations Convention on Biological Diversity of 5 June 1992 and the Declaration of the Responsibilities of Present Generations towards Future Generations of 27 November 1997,

Recalling its Universal Declaration on the Human Genome and Human Rights of 11 November 1997 and its Universal Declaration on Bioethics and Human Rights of 19 October 2005,

Considering that interventions in the human germ-line may become a technical possibility,

Recognizing the human dignity and diversity of individuals, and *emphasizing* that human dignity denies living generations the right to predetermine the characteristics of future individuals and impose their conceptions of good and bad on them,

²⁹⁶ Arie Trouwborst, *Evolution and Status of the Precautionary Principle in International Law* (2002) 286.

²⁹⁷ Confucius, The Quotations Page <<http://www.quotationspage.com/quote/24046.html>> at 21 October 2007.

²⁹⁸ This paragraph is taken from the *Universal Declaration on the Human Genome and Human Rights*, above n 14, preamble.

Solemnly recalling that therefore all kinds of germ-line interventions could be contrary to human dignity,

Having regard to the absolute prohibition of direct germ-line interventions in the European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine of 4 April 1997,

Considering the concerns that arise from uncertainty as to the health, safety and environmental implications of germ-line interventions, and from the longer-term legal, social and ethical issues raised by the prospect of knowing and interfering with a person's inheritable genetic pattern,²⁹⁹

Recognizing humanity's enquiring mind and scientific curiosity as fundamentals of the freedom of research,

Affirming that progress in biology and medicine should be used for the benefit of present and future generations, and that germ-line interventions hold great promise for the treatment and eradication of certain diseases which are genetically transmitted,³⁰⁰

Bearing in mind the importance of procreative liberties and the human right to found a family, and *particularly recognizing* the human right to the highest attainable standard of health,

Emphasizing also the existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in significant advances in the human, social and economic development of their societies,³⁰¹

Emphasizing that research on germ-line interventions should fully respect human dignity, freedom and human rights, as well as the prohibition of all forms of discrimination based on genetic characteristics,³⁰²

Bearing in mind, and without prejudice to, the international instruments which could have a bearing on the applications of genetics in the field of intellectual property,³⁰³

Recalling 22 C/Resolution 13.1, 23 C/Resolution 13.1, 24 C/Resolution 13.1, 25 C/Resolutions 5.2 and 7.3, 27 C/Resolution 5.15 and 28 C/Resolutions 0.12, 2.1 and 2.2, urging UNESCO to promote and develop ethical studies, and the actions arising out of them, on the consequences of scientific and technological progress in the fields of biology and genetics, within the framework of respect for human rights and fundamental freedoms,³⁰⁴

Adopts the present Declaration.

²⁹⁹ Adapted from *Recommendation 934(1982) on genetic engineering*, above n 267, para 2.

³⁰⁰ Adapted from *Recommendation 934 on genetic engineering*, above n 267, para 4(c).

³⁰¹ Adapted from the *Draft comprehensive and integral international convention on the protection and promotion of the rights and dignity of persons with disabilities*, Report of the Working Group, UN Doc A/AC.265/2004/WG.1 [8] (2005).

³⁰² *Universal Declaration on the Human Genome and Human Rights*, above n 14, preamble.

³⁰³ Adapted from the *Universal Declaration on the Human Genome and Human Rights*, *ibid.*

³⁰⁴ *Universal Declaration on the Human Genome and Human Rights*, *ibid.*

A. Human dignity and the human genome³⁰⁵

Article 1

The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.

Article 2

- (a) Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.
- (b) That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.

Article 3

The human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individual's natural and social environment, including the individual's state of health, living conditions, nutrition and education.

Article 4

The human genome in its natural state shall not give rise to financial gains.

B. Prohibition of non-therapeutic germ-line interventions

Article 5

Germ-line interventions with non-therapeutic purposes, such as the enhancement of traits in the genome of any descendants, shall be prohibited. Subject to compatibility with human dignity, human rights and fundamental freedoms, any intervention seeking to introduce any modification in the genome of any descendants may only be undertaken for preventive, diagnostic and therapeutic purposes.

Article 6

- (a) As for the distinction between non-therapeutic and therapeutic purposes of germ-line interventions all interventions shall be regarded as *prima facie* non-therapeutic.
- (b) Anticipating the probable progress in research on and safety of germ-line interventions, the International Bioethics Committee of UNESCO, States and relevant organizations, such as the World Health Organization, should contribute to the drawing up of a list of diseases whose seriousness could justify the interference with the germ-line. Progress in research and the safety of according procedures shall be given due regard in the risk-benefit assessment.
- (c) The inclusion of a disease on the list shall be determined, *inter alia*, by the probability of the expression of the trait and the potential impact the gene in its natural state would have on potential offspring concerning survivability, the potential impairment of the range of opportunities in life, and the probable amount of pain and suffering for descendants.³⁰⁶

Article 7

Scientific and technological progress should not in any way impair or compromise the preservation of the human species.

³⁰⁵ Part A is taken from the *Universal Declaration on the Human Genome and Human Rights*, *ibid.*

³⁰⁶ Buchanan et al, above n 3, 114-5.

C. Implementation of the Declaration³⁰⁷

Article 8

States should make every effort to promote the prohibition laid down in this Declaration and should, by means of all appropriate measures, promote its implementation.

Article 9

The International Bioethics Committee of UNESCO should contribute to the further examination of issues raised by the future applications of germ-line interventions for preventive, diagnostic and therapeutic purposes. It should organize appropriate consultations with parties concerned, such as vulnerable groups. It should make recommendations, in accordance with UNESCO's statutory procedures, addressed to the General Conference and give advice concerning the follow-up of this Declaration, in particular regarding the compatibility of those interventions with human dignity.

³⁰⁷ Adapted from the *Universal Declaration on the Human Genome and Human Rights*, above n 14, arts 22, 24.