Tying Prometheus Down: the International Law of Human Genetic Manipulation

Stephen P. Marks

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Tying Prometheus Down: The International Law of Human Genetic Manipulation

Stephen P. Marks*

"Le jour est venu que l'homme, se rendant moins dépendant de la nature, devient l'esclave de l'anti-nature, la contre-nature, fruit de la science de la nature."

Paul Valéry

I. INTRODUCTION

The growing literature on the bioethics of the human genome has begun to extend into international law. In particular, the field of genetic engineering, which began some thirty years ago, and is rapidly evolving due to the spectacular growth of biotechnology, has been the subject of international law-making. This field is fraught, however, with controversy due to the uncertainty about the risks involved, the deep philosophical implications, and the economic stakes. The focus of this article is the state of international law relating to the potentially harmful technological manipulation of the human genome, primarily through human reproductive cloning and inheritable genetic modification (germline genetic engineering). 2

A central concern is with those methods that some fear will threaten human existence as we know it because, in this view, the genome of future generations will undergo unpredictable mutations and thus alter human nature itself. Others see in

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* François-Xavier Bagnoud Professor of Health and Human Rights at the Harvard School of Public Health, where he is also the Director of the François-Xavier Bagnoud Center for Health and Human Rights. Professor Marks is a member of the Group of Experts on Human Rights and Biotechnology, convened by the High Commissioner for Human Rights. The author gratefully acknowledges the research assistance of Jean Swieca, Executive Editor, Virginia Environmental Law Journal, University of Virginia School of Law.


2. Such efforts are sometimes referred to as "species altering technology" or "human genetic engineering," but such appellations are misleading since numerous widely unobjectionable interventions, such as in vitro fertilization, therapeutic abortion, or even selection of whom to marry and whether to procreate alter the species in the sense that they change the genes that are passed on into the gene pool.
this technology the promise of improving human well-being by eliminating life-threatening diseases and enhancing the quality of life and the capacities of human beings. The Human Genome Project ("HGP") has fueled perceptions that genetic manipulation can result in either the improvement of human lives or uncontrollable mutation and economic exploitation. International law cannot resolve this tension between hope for, and fear of, advances in biotechnology and genetics, but it is already deeply engaged in the issue through international trade and intellectual property law, human rights law, and specific instruments relating to biomedicine.

International legal regulation is required either to protect humans from potential harm—an interest all governments share—or to protect proprietary or financial interests of significance to international commerce—a concern of governments supportive of the business interests of individuals or corporations under their jurisdiction. What international law there is in this field appears to respond to these two sets of often conflicting concerns.

I will begin with the assumptions underlying the specific instruments of international law that address genetic manipulation and then focus on the human rights implications of these technologies. In conclusion, I will refer to the push for new treaties coming from several directions.

II. UNDERLYING ASSUMPTIONS OF THE INTERNATIONAL LAW OF HUMAN GENETIC MANIPULATION

Developments in biotechnology involving modification of the genetic structure of human beings have attracted the attention of ethicists and legislators at the national level in Europe and North America, but much less so in developing countries for the obvious reason that both research and the potential application of such technology are beyond the means of a majority of countries in the political South. The three principal instruments of international law that address human genetic manipulation all result from initiatives by European states, namely the Universal Declaration on the Human Genome and Human Rights ("UNESCO Declaration" or "Declaration"), the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine ("European Biomedicine Convention"), and the Additional Protocol on the Prohibition of Cloning Human Beings ("Additional Protocol"). A fourth instrument, in preparation, is the Franco-German proposal to the United Nations for an International Convention Against Reproductive Cloning of Human Beings. These instruments are based on several

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3. See Letter to the Secretary General, from the Charges d'affaires a.i. of the Permanent Missions of France and Germany to the United Nations addressed to the Secretary General, Request for the Inclusion of a Supplementary Item in the Agenda of the Fifty-sixth Session: International Convention Against the Reproductive Cloning of Human Beings, UN Doc No A/56/192 (Aug 7, 2001). The General Assembly decided to create an ad hoc committee to consider elaborating such a convention and to
assumptions underlying the current thinking on this subject in Europe, where the principal instruments have been drafted. Other conflicting assumptions are more common in the United States, although these geographical distinctions have many exceptions.

A. ESSENTIALIST AND WELFARE STATE ATTITUDES

The impetus for the existing instruments in international law comes primarily from Europe (which Canada often joins) and reflects assumptions about the essence of human existence and the welfare function of the state. The principal author of the UNESCO Declaration, Noëlle Lenoir, former Justice of the French Constitutional Court and President of the European Group on Ethics in Science and New Technology, is quite direct in attributing the underlying ideas of the UNESCO Declaration and the European Biomedicine Convention to a "European Perspective." This is not to diminish the role of many other members of the International Bioethics Committee, who drafted the Declaration, and who represented other regions, as did the member states of UNESCO in adopting the text. The European perspective focuses primarily on three areas of serious concern, some of which are shared by many groups in the United States and elsewhere: preservation of nature; protection from economic exploitation; and prudence in the face of uncertainty.

Concerns over the preservation of nature reflect an attachment to the uniqueness and sanctity of human DNA and to biodiversity and the genetic complexity of species as they have evolved over millennia. The European attitude, shared by many in governmental, scientific, and nongovernmental circles, has been characterized in rather unflattering terms by Eric Juengst, who denounces as misguided the European attachment to our "species integrity," explaining that it suggests that taxonomy might determine a creature's moral status, and that it is conceivable only those creatures that display the motley collection of genes human beings share (at some instant) warrant basic rights. Again, this itself is a form of "altering" our gene pool that we should spurn as moral idolatry.

The "species integrity" camp has numerous proponents on both sides of the Atlantic that are currently advancing projects for at least three international treaties that support their position. One is an outgrowth of the September 2001 conference at Boston University to draft a "Convention on the Preservation of the Human Species." The second is being prepared by Jeremy Rifkin, the "Treaty to Protect the


5. Parties to this treaty would agree to
Genetic Common." The third is a proposal to draft an international convention on the human genome under a common heritage of humankind regime.

A second assumption relates to the European opposition to financial gain from genetic engineering. This opposition is in part due to the role of European governments in protecting citizens against exploitation by private business and providing for their health and well-being. This premise of protection from financial gain appears in both the European Biomedicine Convention and the UNESCO Declaration. Related to concerns over financial gain is the rejection of the "instrumentalization" of human beings. The essential point of this argument is the Kantian principle that an individual should never be used exclusively as a means to an end. Such would be the case, goes the argument, if genetic manipulation of human DNA relegated people to being mere products.

The "precautionary principle" holds that risky activity should be limited in proportion to the uncertainty and potential gravity of its consequences. It prevails in Europe but is also widely supported in the US. This principle has been interpreted as encompassing four component principles that should govern the use of any new technology, process, activity, or chemical: the duty to prevent harm; the burden of proof of harmlessness on the proponents rather than the public; the duty to examine all alternatives; and the need for open, informed, and democratic decisionmaking. Proponents argue that, given the hazards of gene-modification technologies, "the precautionary principle represents a scientific improvement over standard risk-benefit analysis."

condemn and ... take all reasonable action, including the adoption of criminal laws, to prohibit anyone from initiating or attempting to initiate a human pregnancy or other form of gestation, using embryos, or reproductive cells which have undergone intentional inheritable genetic modification ... and to prohibit anyone from utilizing somatic cell nuclear transfer or any other cloning technique for the purpose of initiating or attempting to initiate a human pregnancy.

It also calls for the creation of a Commission of the Preservation of the Human Species. Text dated Oct 10, 2001 (on file with the author).

Certain considerations reflecting different, more utilitarian philosophical assumptions tend to be raised in the United States and draw upon neoliberal economic preferences. These considerations favor the freedom of individuals to select the technology that will improve their lives regardless of social consequences, and the freedom of individuals and corporations to pursue financial gain through exploitation of new technologies.

The assumption of freedom and autonomy of the individual has a libertarian corollary that "capitalistic acts between consenting adults are none of its [the state's] business." According to this perspective, financial gain from patenting life forms, owning genotypes, and selling gene therapy or cloning, is viewed as either morally neutral or positive. Moreover, "consumers" of genetic manipulation are regarded as free to do what they wish to their bodies, including altering their own genetic makeup or that of their offspring.

From the ethical perspective, arguments for a new eugenics include conditional support for human genetic manipulation. After exposing the errors of the eugenics movement of the past, particularly the Nazi efforts to produce a super race characterized by racism, class bias, and coercion, the authors of From Chance to Choice show how new eugenics seeks to preserve the ethically valid motivation of the movement. Daniel Wikler explains that "[n]o one objects in principle to using what we know of the science of heredity to improve the chances of future generations for achieving greater well-being. What arouses passionate debate are the means to be used." He and his coauthors explain that

[r]eprehensible as much of the eugenic program was, there is something unobjectionable and perhaps even morally required in the part of its motivation that sought to endow future generations with genes that might enable their lives to go better. We need not abandon this motivation if we can pursue it justly.

Patent protection is a third assumption of the neoliberal position. Instruments relating to intellectual property and trade favor technology transfer and commercialization of developments in biotechnology. While protected in all industrialized countries, patents take on a particularly high level of protection in the

13. Allen Buchanan, et al, From Chance to Choice: Genetics and Justice 27-60 (Cambridge 2000). The authors underscore the variation in the scientific and political content of the eugenics movement. For example, Mario Capecchi notes, "the pressure to initiate germline gene therapy will not likely come from governments or dictators with a desire to make a super race, but rather from parents." Mario R. Capecchi, Human Germline Gene Therapy, in Gregory Stock and John Campbell, eds, Engineering the Human Germline 31, 32 (Oxford 2000).
United States. US law regarding subject matter patentability classifies as patentable, "any new and useful process, machine, manufacture, or composition of matter, or any new or useful improvement thereof."16 US patent law appears to take the view that isolated human DNA is a material possession that may be bought, sold, licensed, and owned.

The European Union addressed the issue of patenting life forms in a 1998 EU Directive: "An element isolated from the human body or otherwise produced by means of a technical process, including the sequence or partial sequence of a gene, may constitute a patentable invention, even if the structure of that element is identical to that of a natural element."17 The Directive's opponents within the EU view patenting human DNA as the commodification of life itself, a process that turns legal subjects (persons) into legal objects and thus infringes upon human dignity. This position is reflected in the UNESCO Declaration and the European Biomedicine Convention. The EU Directive acknowledges this concern, but does not, in the view of its critics, adequately address it.

Finally, it should be noted that the Agreement on Trade-Related Aspects of Intellectual Property Rights ("TRIPS") provides that "patents shall be available for any inventions, whether products or processes, in all fields of technology, provided that they are new, involve an inventive step and are capable of industrial application."18 Thus, international intellectual property law tends to favor market forces in deciding whether genetic knowledge and methods of genome manipulation can be traded for financial gain.

The predominant attitudes reflect "a fundamental division of opinion between seeing human life in terms of its intrinsic value, or in terms of its utilitarian value. A gene is either life itself or a useful piece of kit."19 The divergent perspectives appear to combine both philosophical and economic considerations, essentialist with a penchant for the welfare state, on the one hand, and utilitarian with a neoliberal accent, on the other. These two broad sets of assumptions are summarized on the following table, with the caveat that these generalizations have numerous exceptions.

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ESSENTIALIST AND WELFARE STATE PERSPECTIVE

- Human genetic makeup is sacred; its "natural order" should not be tampered with.
- The state should provide access to benefits (positive rights).
- The state has a duty to equalize opportunity and ensure basic needs (equality principle).
- Property rights imply access to the fruits of scientific achievement accessible by all.
- Financial gain should be limited/forbidden for certain activities.
- New technology should not be used if the consequences are uncertain (precautionary principle).

UTILITARIAN AND NEOLIBERAL PERSPECTIVE

- Humans are physical matter; their bodies are material that may be improved upon, sold, or traded if free and informed consent is given.
- The state should refrain from interfering with private activity (negative rights).
- Private actors should be unregulated so long as they do not interfere with others (liberty principle).
- Property rights imply the right to exclude others from access.
- Financial gain should be the ultimate end of economic activity.
- Unimpeded market forces should determine optimal "efficient" risk-level (laissez faire principle).

III. HUMAN RIGHTS ISSUES OF HUMAN GENETIC MANIPULATION

Human rights are frequently alluded to or mentioned explicitly in the existing instruments of international law on human genetic manipulation. International instruments relating to human rights provide ambiguous standards by which the human impact of biotechnological applications may be judged and are invoked to support the conflicting assumptions mentioned in the previous section. The impact of genetic engineering on human rights was anticipated decades ago. In 1971, George Brand catalogued the possibilities, warning that "[i]t is easy, but dangerous, to dismiss all of these possibilities as science fiction." The scientific complexity of the issues, the uncertainty of the technology, the limited number of governments with an interest in regulation, and the divergent philosophical assumptions of those governments contribute to the difficulty of adopting international norms in this area. The

20. Brand referred to artificial insemination; in vitro fertilization; parthenogenesis; choice of sex of offspring; creation of human beings by an asexual process called cloning; manipulation of the DNA molecule so as to interfere with the processes of heredity ("genetic surgery"); the improvement, by procedures adopted before birth, of the future intelligence of a child, and the creation of part-human chimeras.

following broad-brush reflections on the human rights implications of human genetic manipulation illustrate that difficulty. They will show that most international human rights standards lend themselves to both sides of the argument. To facilitate analysis of the fifteen rights involved, I have grouped them—somewhat arbitrarily—into three broad categories.

A. RIGHTS RELATING TO THE NATURE AND AUTONOMY OF THE HUMAN PERSON

The rights in this category (dignity, life, identity, non-discrimination, privacy, information, free consent, and intellectual property) refer to elements of the essential nature of human beings or to the basic freedom to act as an autonomous agent.

The human right to dignity has been treated as the cornerstone of human rights. Echoing the Universal Declaration's reference to "the inherent dignity... of all," the UNESCO Declaration affirms that "dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity," and characterizes human reproductive cloning as one of the "practices which are contrary to human dignity [and which] shall not be permitted." The aim of the European Biomedicine Convention is "to safeguard human dignity and the fundamental rights and freedoms of the individual with regard to the application of biology and medicine." States parties agree to "protect the dignity and identity of all human beings." The protocol adds that "[t]he deliberate creation of genetically identical human beings is contrary to human dignity and thus constitutes a misuse of biology and medicine."

Dignity is not well defined in international law but, in its normal meaning as the state of being worthy of honor or respect and not subjected to humiliation, it would not necessarily be violated in the case of a cloned individual any more than it would in the case of a "natural" twin. The first successful clones would probably suffer a lack of dignity by being the object of much curiosity, publicity, and even scorn. However, such attitudes might diminish, as they have with respect to "test tube babies" since in vitro fertilization ("IVF") technology has become more widely used. Stereotyping by

22. Id at art 11.
23. European Biomedicine Convention at Preamble (cited in note 8).
24. Id at art 1. The drafters' intention is clear on the central value of dignity: "The concept of human dignity, which is also highlighted, constitutes the essential value to be upheld. It is the basis of most of the values emphasized in the Convention." Explanatory Report to the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine, reprinted in 36 ILM 817, 828 (1997).
race and sexual preference often violates the dignity of the targeted persons; however, education and other means of influencing social behavior used to eliminate such stereotyping could also be used to protect the dignity of humans produced by asexual reproduction. Experience with IVF also raises doubts as to the dangers of the “instrumentalization” of human reproduction by cloning. A human being does not necessarily lose dignity merely because a complex technique was used in his or her creation. However, should cloning or germline genetic manipulation result in physical or behavioral traits perceived by the general population as “freakish,” then the application of these forms of biotechnology may indeed violate human dignity.

The right to identity, frequently invoked along with dignity, does not relate in positive international law to the existential meaning of identity, but rather to civil status. Name and nationality are not likely to be denied people whose genome has been modified by biotechnology. “Family relations” of a clone are more problematic; a clone would be both a sibling and a child of its “parent.” However, as a matter of legal identity, the clones would be the children of those who take legal responsibility for their upbringing.

Evelyn Shuster supports the existential sense of identity when she affirms that cloning threatens “rights to personal identity, individuality, and uniqueness.”

Genetic independence comes ... from a unique genetic identity. Because it makes impossible the child's genetic independence, cloning holds that child genetic prisoner of another person's genome. The child is robbed of the freedom to become who he/she is . . . the one unique person who lives and dies . . . . In short, cloning violates the child's right to an open future.

Because there are no recognized rights to “uniqueness” (although it is mentioned in the UNESCO Declaration) or “an open future” in positive human rights law, Shuster makes recourse to the right to dignity and the prohibition of slavery and cruel, inhuman, or degrading treatment, as well as the child's right to identity and to education directed to the development of the child's personality. Unfortunately, none of these recognized human rights contains an explicit reference to uniqueness or an open future. It has also been argued that there is a human right “of each newborn


27. See International Covenant on Civil and Political Rights ("ICCPR"), art 24, 999 UNTS 171 (1967) ("Every child shall be registered . . . and have a name . . . [and] the right to acquire a nationality."); United Nations Convention on the Rights of the Child, art 8, General Assembly Res No 44/25, UN Doc No A/RES/44/25 (1990) (asserting "[t]he right of the child to preserve his or her identity, including nationality, name and family relations").


29. Id at 40.
child to be a complete surprise to its parents." This idea, like "uniqueness" and existential "identity," may be emotionally appealing but it is not part of current international human rights law.

The rights to non-discrimination and to equal protection of the law are a concern of both the UNESCO and Council of Europe texts, as well as the Charter of Fundamental Rights of the European Union ("European Charter"). Discrimination issues arise primarily with respect to genetic testing or screening, the results of which could induce prospective or current employers or insurers to exclude persons from employment or coverage whose propensity to disease or other health conditions is high as revealed by their gene sequencing. Such concerns would extend to persons created through reproductive cloning or modified by germline engineering, since their particular genetic heritage would have been identified, and the dangers represented by the known genes or by unknown side effects may lead employers or insurers to consider them too great a risk. This issue is already the subject of litigation in the United States.

Persons created or altered through genetic manipulation might also be regarded as benefiting inequitably from positive discrimination. Their genes may have been selected in order to make them smarter, stronger, faster, or more creative, thereby giving them advantages over people who result from normal sexual reproduction. The ban against discrimination would thus favor them over persons with lesser mental or physical capabilities. Moreover, in most cases, they would have benefited from a form of discrimination by having had access to expensive biotechnology ("boutique medicine"), medicine that less well-off people could not afford and that is unlikely to be offered through public health services.

The right to privacy and the related right to seek, receive, and impart information, have both been included in the emerging international law of human genetic manipulation. The UNESCO Declaration provides that "[g]enetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions set by law." The European Biomedicine Convention at Article 10 provides that "[e]veryone has the right to respect for private life in relation to information about his or her health

31. In an editorial in Science in 1989, Daniel Koshland wrote:
   A genome sequence should not be a precondition of employment, and legislation might be needed if that problem were to arise. However, less accurate data of the same type would be available today from family histories, and that does not seem to be part of current employment forms. If more accurate information provides temptation for abuse, action will be needed.
32. UNESCO Declaration at art 7 (cited in note 9).
Tying Prometheus Down

... [and] to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.”

The protection of privacy already includes health-related information. Human genetic data collection only increases the need for protection. People whose DNA is analyzed also have a right to know who is collecting the information, why, where it is stored, and who has access to it. Sometimes their rights are protected by the destruction of the genetic information.

Experimental and therapeutic interventions for the purpose of genetic engineering raise special problems regarding “free consent to medical or scientific experimentation.” The UNESCO Declaration and the European Biomedicine Convention require a risk-benefit assessment with prior, free, and informed consent. However, most decisions will require informed consent even where the risk-benefit assessment is impossible. Buchanan and others remind us that “genetic interventions leave room for many unintended genetic effects with unknown risks.” They insightfully point out that uncertainty can only be removed by human experimentation, which would be ethically impossible with germline therapy “since consent cannot be obtained from future offspring who might be affected, nor from the embryos upon whom the intervention would be performed.”

Paradoxically, intellectual property rights appear to protect biotech companies against the claims that their patents violate human rights, even though they derive from a human right, namely “the right of everyone . . . to benefit from the protection of the moral and material interests resulting from any scientific . . . production of which he is the author.” In practice, of course, biotechnology companies rely on intellectual property rights to protect their inventions and patents, including methods of human genetic manipulation and even genotypes, and use them for commercial gain. But, is the “human right” to ownership in patents compatible with the human rights principle of Article 4 of the UNESCO Declaration and Article 21 of the European Biomedicine Convention that bar economic gain from the exploitation of

33. In a US case in 1998, a Boston court found that taking DNA samples as part of routine blood testing of prisoners without permission was a clear violation of human rights. See Landry v Harbarger, 1998 Mass Super LEXIS 479. See also Martine Jacob, DNA in the Dock, 53 UNESCO Courier 37, 39 (Apr 2000) (noting that Germany, Austria, Finland, Sweden, Denmark, and the Netherlands have all ordered the destruction of the DNA samples held in police databases and laboratories once the suspect’s identity has been established; though, the UK places no limit on how long that data can be kept and periods vary among states in the US).
34. ICCPR at art 7 (cited in note 27).
36. Id at 194.
The researcher who makes great strides in stem cell research and discovers a means of genetic engineering to eliminate a gene linked to Alzheimer's disease, would, from a human rights perspective, deserve protection of his or her "moral and material interests." What if the patient suffered from terrible health consequences as a result? The deterioration in the patient's health, including premature death, could be considered the "destruction" of rights to life and to health, contrary to the principle that no provision of the Covenants, such as the right to intellectual property, may be used to justify "any State, group or person... engaging in any activity or... performing any act aimed at the destruction of any of the rights or freedoms recognized herein." 

The TRIPS agreement allows World Trade Organization ("WTO") members to exclude from patentability inventions "to protect human, animal, or plant life or health" as well as "diagnostic, therapeutic and surgical methods for the treatment of humans." The ambiguities of such language can only be removed by further standard-setting or by case law, assuming the Dispute Settlement Body and the Appellate Body will be able to balance intellectual property and other human rights as cases arise.

B. RIGHTS RELATING TO PHYSICAL AND MENTAL INTEGRITY AND WELL-BEING

At least four other rights concern human well-being, both physical and mental. The European Charter of Fundamental Rights includes a general provision on physical and mental integrity, which captures the essentialist assumptions mentioned above.

The claim that human genetic manipulation threatens the right to life implies, in the language of the international human rights texts, the arbitrary taking of life. This would not be the case if human reproductive cloning and germline gene therapy were understood as processes to create and protect life. However, the Council for Genetic Responsibility proposes a different understanding of this right, namely the claim that "all people have the right to have been conceived, gestated, and born without genetic

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38. See Council for Responsible Genetics ("CRG"), 13 Gene Watch: A Bulletin of the Council for Responsible Genetics 3 (Apr 2000) (proposing a Genetic Bill of Rights, in which Article 2 provides "[a]ll people have the right to a world in which living organisms cannot be patented, including human being... and all their parts.").

39. ICCPR at art 7 (cited in note 27).

40. See TRIPS Agreement at art 27 (cited in note 18).

41. See Charter of Fundamental Rights of the European Union, art 3, 2000 OJ (C 364) 10 (prohibiting "eugenic practices, in particular those aiming at the selection of persons...[and] reproductive cloning of human beings").
That is a rather odd twist on the right to life, since it is a right retroactively to have been born a certain way, which suggests a concomitant remedy for “wrongful life” or “wrongful disability.” It is not unlike a recent French award of substantial damages to the mother of a child with Down’s Syndrome because the doctor had not informed her of the likelihood of the disease and the possibility to abort the fetus, thus establishing a legal right never to have been born and to sue doctors that attended the pregnancy.

The matter takes on greater complexity in the context of the duty of states, under the inherent right to life of the child, to “ensure . . . the survival and development of the child.” Some—including the Roman Catholic Church—will argue that a gamete or embryo has the right to survival and development. This argument is behind the efforts to ban stem cell research and the highly unsettled question of what constitutes life. But, one could also argue that parents should be able to choose any means, including gene therapy, to protect the survival and development of their child.

International human rights law includes the prevention and repression of a growing number of large scale human rights violations qualified as international crimes, including torture, slavery, terrorism, genocide, and crimes against humanity. Even if suffering that might result from cloning or germline genetic manipulation did not reach the threshold of torture, one can imagine physical or mental conditions of a cloned individual or genetically altered person that would make their life “cruel.” Cruelty might also arise from stigmatizing of disability by others who see special needs as “deformities” to be ridiculed or pitied. Paradoxically, such attitudes could reinforce the contention that physical and mental “abnormalities” resulting from human genetic manipulation constitute “cruel treatment,” in violation of human rights.

George Annas points out that genetic manipulation could be viewed as “inhuman” treatment. He refers to the danger of creating a person who would be “viewed as a new species or a subspecies of human and thus not necessarily a possessor of human rights.” If the physical traits were altered to a sufficient degree and (as suggested by Annas) the altered individual were not able to reproduce other humans, then some would regard the clone as inhuman, making it more difficult to accuse those who authorized or carried out the procedures as responsible for “inhuman treatment.”

42. See CRG, 13 Gene Watch at 3 (asserting such a right at Article 10 in its Genetic Bill of Rights) (cited in note 38).
43. See French Court Confirms Handicapped’s Right not to be Born, Agence France Presse (Nov 28, 2001); Nanette van der Laan, France Debates Right not to be Born, Christian Science Monitor (Dec 7, 2001). On wrongful life suits in general, see Buchanan, et al, From Chance to Choice at 232–33 (cited in note 13).
As for slavery, one could imagine the extreme scenario frequently portrayed in science fiction of a well-funded group or government insane enough to attempt to clone large numbers of specially gifted humans for military, labor, or other tasks. Such armies could reasonably be considered slaves or persons subjected to forced labor, in violation of human rights law. Annas goes further, arguing that human replication cloning, and other forms of genetic engineering “fit into a new category of ‘crimes against humanity.’”\(^46\) Unless a democratic world body agreed that such experiments should go forward, he argues, carrying them out would be “a terrorist act.”\(^6\) He fears genocide either through the mass killing of genetically altered “posthumans” (because “we will see them as a threat to us”) or by the posthumans deciding that we should be “slaughtered preemptively.”\(^47\) Qualifying scientifically hazardous experiments and possible disregard for human welfare by the biotech industry in the pursuit of profits as international criminal behavior is perhaps a useful attention-grabbing metaphor, but a questionable application of international criminal law. However, Annas—whose path-breaking insights I generally applaud—intends it literally, as he suggests referral to the International Criminal Court.\(^48\) Applying a standard of criminal negligence appears more plausible and absolute liability for such ultra-hazardous activity might offer a deterrent to such abuses.

The right to health is clearly the most ambiguous human right at issue. The Committee on Economic, Social and Cultural Rights (“CESCR”) considered, in its General Comment 14, that the right of everyone to the enjoyment of the highest attainable standard of physical and mental health must be “conducive to living a life of dignity.”\(^49\) In fact, the Committee enumerated fourteen rights related to the right to health and on which that right depends. Most human rights treaties, including the European Biomedicine Convention, include a formulation of this right. General Comment 14 notes that the provision in the International Covenant on Economic, Social, and Cultural Rights (“ICESCR”) on the reduction of the stillbirth rate and of infant mortality, as well as the healthy development of the child, “may be understood as requiring measures to improve child and maternal health, sexual and reproductive


\(^{46}\) Annas, 49 Emory L J at 778 (cited in note 45).


\(^{48}\) Annas, 49 Emory L J at 771, 780 (cited in note 45).

health services, including access to family planning, pre- and post-natal care, emergency obstetric services and access to information, as well as to resources necessary to act on that information.\textsuperscript{50} It is a matter of opinion whether gene modification can be classified among such services. The General Comment also acknowledges that genetic factors play a role in determining an individual’s health, but does not address specifically genetic manipulation or cloning.

Following the Committee’s three types or levels of obligations of State parties,\textsuperscript{51} one could argue that a state’s obligation to respect the right to health requires that no government agency participate in or fund dangerous genetic manipulation; that the obligation to protect includes preventing the biotech industry from engaging in such activity; and that its obligation to fulfill means that its legislative, executive, and judicial branches act to suppress such activities, and inform the health professions and the population of the dangers. Using contrary assumptions about the risks and moral implications, these same obligations could be invoked to engage the national health system and other organs of the state in tolerating, promoting, and practicing genetic manipulation. At the current stage of knowledge and ethical debate, national policies and legislation show a wide divergence of laws and practice.\textsuperscript{52}

A significant sub-area of the right to health concerns reproductive rights.\textsuperscript{53} Regarding the threat to women’s reproductive rights, Marcy Darnovsky writes,

\textquote{H}uman cloning and germline engineering would move decisions about reproduction further away from women, not only toward doctors and technicians but also toward marketers proffering the ‘enhancements’ developed by biotech companies. Women could find themselves simultaneously losing ever more control of their own childbearing experiences, and subject to vastly increased pressures to produce the perfect baby.\textsuperscript{54}

The CESCR includes within the right to health “the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical

\begin{footnotesize}
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\item Id at para 14.
\item Id at para 33.
\item See Global Lawyers and Physicians, Database of Global Policies on Human Cloning and Germ-line Engineering, available online at <http://www.glphr.org/genetic/genetic.htm> (visited Mar 24, 2002) (a systematic compilation of these national laws, as well as a complete collection of national and international references on both human cloning and germline engineering).
\item See Convention on the Elimination of All Forms of Discrimination Against Women, art 16(1)(e), 1249 UNTS 13 (1981) (asserting the right of “men and women... to decide freely and responsibly on the number and spacing of their children”); Report of the International Conference on Population and Development, para 7.2, UN Doc No A/CONF.171/13 (1994) (asserting a right of people “to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice”).
\item Marcy Darnovsky, Human Germline Engineering and Cloning as Women’s Issues, 14 Gene Watch 1 (July 2001).
\end{enumerate}
\end{footnotesize}
A parent's decision to create a child asexually or to use germline genetic engineering is arguably part of such sexual and reproductive freedom. It could also be argued that the parent provides the requisite consent of the resultant child to the experiment. The European Biomedicine Convention would limit the parent's choice of treatment by requiring that “[a]n intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.”

The authors of From Chance to Choice place this issue in the broader context of the conflict between liberty and intergenerational harm prevention. They posit the situation in which “the obligation to prevent genetically transmitted harms is strong enough to justify limiting or interfering with reproductive freedom,” especially when the harm is transmitted over generations. They leave open the moral possibility of coercive non-conception (sterilization), germline therapy, and abortion to prevent cumulative harm to future generations, but tend to favor reproductive freedom over such coercion because the benefit to any one individual in the future is very small compared to the importance of reproductive freedom.

**C. Rights dealing with Social Relations and Participation**

Finally, five rights are concerned with the participation of humans in social relations, such as the right to education, children's rights, the right to found a family, the right to enjoy the benefits of scientific progress, and the right to scientific research.

The right to education includes the directive that “education shall be directed to the full development of the human personality and the sense of its dignity” and that “education of the child shall be directed to the development of the child’s personality, talents and mental and physical abilities to their fullest potential.” These texts refer to traditional notions of child development in psychology, not the particular development problem that might arise if a child's genetically determined development potential is selected by the parent. The challenge to the right to education comes both from efforts to improve the “personality” of the child (such as friendly disposition, intellectual capacity to master complex tasks) through successful germline genetic engineering and from failed interventions resulting in unexpected psychological responses (such as increased anxiety or even psychotic reactions). It is, of course, highly speculative whether genes related to personality can be transmitted through

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55. General Comment 14 at para 8 (cited in note 49).
56. European Biomedicine Convention at art 13 (cited in note 8).
58. See id at 204–57.
59. ICESCR at art 12 (cited in note 37).
germline therapy. Assuming it is possible, the human rights framework does not—and understandably so—indicate whether the “human personality” to be developed is different in a genetically altered individual than it is in a child resulting from sexual reproduction without genetic manipulation. If the genetic manipulation fails, one might consider that the right to education has been violated by the parents and the medical team involved because the potential has been negatively altered. The intention may have been to create a happy and well-adjusted child with enhanced physical and mental talents, but if those enhanced qualities are not attained, then the criterion of “fullest potential” is clearly not met. Similarly, the creation of a person with genetically enhanced physical and mental capabilities may have a negative effect on the education of “normally” endowed people.

Most of the human rights discussed so far concern the rights of offspring and therefore are children’s rights, the underlying idea of which is the best interest of the child and special protection, because children do not have the capacity to ensure the realization of their rights in the same way as adults. The Convention on the Rights of the Child requires parents “to provide direction and guidance in the exercise by the child of the rights [in the Convention].”61 One may query whether this duty is met when a parent decides for the child what physical and mental traits it will have or—where the procedure produces unintended results—creates for the child a lifelong dependency. These voluntary acts by the parents are not directly related to the child’s exercise of rights in the Convention but they certainly influence the child’s range of choices in exercising those rights, particularly with respect to the “right of the child to . . . the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.”62 Proponents of genetic manipulation might argue that intervention in a child’s genetic make up raises the standard of the child’s health or constitutes a facility for the treatment of illness.

Another children’s rights issue is the alleged right to life of the unborn. Some who oppose voluntary termination of pregnancy argue that a gamete or embryo has the right to survival and development, and therefore, producing numerous embryos in order to remove the nucleus from one and destroy the others would violate the rights of all those potential children. However, this is a rather radical theological position, unsupported by the current interpretation of the right to life and children’s rights in international human rights law.

In a different vein, an uncompromising argument against cloning as a violation of children’s rights has been made by Evelyne Shuster.63 She argues that cloning is fundamentally destructive of the rights of children and their human dignity. Specifically, she claims that cloning robs children of their rights to personal identity,

61. Id at art 5.
62. Id at art 24(11).
63. See Shuster, My Clone, Myself at 37-45 (cited in note 28).
individuality, and uniqueness, commodifies children by treating them as interchangeable, and changes the way we think about sexuality and mortality in disruptive and destructive ways. She proposes a world summit on the future of the human species to protect the integrity of the human species to prevent the powerful biotechnological industries, venture capitalists, and self-serving scientists from deciding for us what is best for our future and the future of our children.

Article 23 of the International Covenant on Civil and Political Rights ("ICCPR") recognizes the right of men and women of marriageable age to marry and to found a family. It is widely recognized that IVF is an acceptable means of implementing this right. One might extend that argument to cloning as a means of founding a family. The covenant does not establish any conditions on the method for founding a family. In fact, cloning may be a means of allowing same-sex couples—where such partnering is recognized as a legitimate arrangement for marriage and founding a family—to produce children having traits of one of the parents without the need—in the case of lesbian couples—of male sperm. Hilary Putnam sees in human cloning a problem for the "moral images of the family," which should "reflect our tolerant and pluralistic values." We should value such an image of the family, he says, rather than designing our children out of "narcissistic and xenophobic" values.

One of the principal arguments in favor of human genetic manipulation is that it constitutes an advance in science and technology that benefits humankind. The internationally recognized right of everyone to enjoy the benefits of scientific progress and its applications supports such an argument. Article 12 of the UNESCO Declaration provides that benefits from advances in biology, genetics, and medicine that concern the human genome, shall be made available to all, with due regard for the dignity and human rights of each individual, and that applications in these fields shall seek to offer relief from suffering, and improve the health of individuals and humankind as a whole.

Consumers wishing to avail themselves of techniques of genetic manipulation and companies proposing to market them can claim such a right. This right is not, on its face, contrary to patent protection since one could argue that patents are designed to encourage advances in biotechnology, and that the benefits therefrom will be made "available to all" after the expiration of the patent. In fact, TRIPS, the principle instrument supporting patents in international trade, states that "the protection and enforcement of intellectual property rights should contribute to the promotion of technological innovation and to the transfer and dissemination of technology, to the mutual advantage of producers and users of technological knowledge and in a manner conducive to social and economic welfare, and to a balance of rights and obligations." The TRIPS Agreement appears to favor the international transfer of technology.

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64. Putnam, Cloning People at 12 (cited in note 30).
65. TRIPS Agreement at art 7 (cited in note 18).
However, the bioethics texts establish a clear hierarchy between human well-being and the interests of science. According to this principle, potential harm to individuals of experiments on genetic manipulation should be adequate to justify measures to limit or halt such experimentation in the interest of science.

Closely related to the right to benefit from scientific progress is the undertaking by States "to respect the freedom indispensable for scientific research and creative activity." A 1974 UNESCO text provides some elements of the definition of freedom of scientific research by recognizing "that open communication of the results, hypotheses and opinions—as suggested by the phrase ‘academic freedom’—lies at the very heart of the scientific process and provides the strongest guarantee of accuracy and objectivity of scientific results." With respect to publicly supported scientific research, UNESCO recommends that member states allow researchers to enjoy "the degree of autonomy appropriate to their task and to the advancement of science and technology" and to take fully into account "that creative activities of scientific researchers should be promoted in the national science policy on the basis of utmost respect for the autonomy and freedom of research necessary to scientific progress." This freedom suggests non-interference by the state in research on human genetic manipulation, although restriction on funding of embryonic stem cell research and banning of human cloning may be consistent with the Recommendation’s reference to member states’ duty to encourage researchers to determine methods which should be humanely, socially, and ecologically responsible.

US legislation banning cloning sometimes specifies that the ban shall not be construed to restrict biomedical and agricultural research or practices unless expressly prohibited herein, including research or practices that involve the use of: (i) somatic cell nuclear transfer or other cloning technologies to clone molecules, including DNA, cells, or tissues; (ii) gene therapy; or (iii) somatic cell nuclear transfer techniques to create animals other than humans.

Lori Anderson has noted that a lower federal court suggested that scholars have a right “to do research and advance the state of man’s knowledge” although other federal courts "have refused to recognize a First Amendment right to scientific inquiry." She concludes, “the government could regulate to protect against compelling harms . . . so

66. See European Biomedicine Convention at art 2 (cited in note 8) (“The interests and welfare of the human being shall prevail over the sole interest of society or science.”).
67. ICESCR at art 15(3) (cited in note 38).
69. Id at para 8.
long as the regulation is no more restrictive on speech than is necessary to further that intent."^{72}

The World Health Assembly recognized, in the context of cloning in human reproduction, "the need to respect the freedom of ethically acceptable scientific activity and to ensure access to the benefits of its applications."^{73} Similarly, the European Biomedicine Convention acknowledges freedom of scientific research and testing for health related research. Both the European Biomedicine Convention and the UNESCO Declaration make an exception to freedom of research where human welfare or human rights would suffer.

**IV. CONCLUSION: TOWARDS A NEW INTERNATIONAL TREATY?**

The preceding discussion should have made evident the tension that exists between two principles of international law, each with underlying philosophical assumptions. The first is the restrictive principle, which draws support from a half century of development of international human rights law, to which proponents of the position that the human species must be preserved appeal in order to place such technology beyond the pale. The opposing principle is the permissive principle, supported by international trade and intellectual property law, and justified by ideas of free markets, free trade, freedom of scientific research, and freedom of choice of consumers. This perspective calls for minimal limitations on the developing and marketing of technologies of human genetic manipulation.

At the governmental level, the Franco-German initiative at the UN is expected to result in a convention banning reproductive human cloning by 2003. In addition, the Commission on Human Rights has requested that the Secretary-General draw up proposals on proper coordination of activities and thinking on bioethics throughout the United Nations system, and consider establishing a working group of independent experts, which would consider the possible follow-up to the Universal Declaration on the Human Genome and Human Rights. The Commission drew

the attention of Governments to the importance of research on the human genome and its applications for the improvement of the health of individuals and mankind as a whole, to the need to safeguard the rights of the individual and his/her dignity, as well as his/her identity and unity, and to the need to protect the confidentiality of genetic data concerning a named person.

The non-governmental initiatives are unlikely to advance unless they join forces with the European initiative at the UN. If the eventual treaty appeals to a large

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number of states, it may be because it will not satisfy either the essentialist/welfare state or the utilitarian/neoliberal camp and will not constrain governments beyond what they have already accepted. At the same time, the convergence of the political left and right, as well as the religious and secular advocates on the issue of human cloning, may bring enough pressure for the United States to join the treaty.

Scholars, scientists, and science fiction writers have predicted for generations that advanced genetic and medical technology could modify the genetic make-up of humans as a means of alleviating human suffering and improving the quality of life. Progress in reproductive health technology has already allowed thousands of people to make choices affecting the genetic heritage of their offspring. Embryonic stem cell research holds out hope for other advances. At the same time, the prospects for altering inheritable genes through human reproductive cloning and germline gene therapy have raised fears that such tampering with the gene pool would result in profound and irreparable harm to human existence. The most authoritative consultative bodies, such as those convened by the World Health Organization and the now defunct National Bioethics Advisory Commission, have acknowledged that it is premature to regulate beyond a moratorium on human cloning.

In the meantime, specific issues that call for the application of international law will be settled by reconciling human rights and intellectual property law. The latter is supported by the dominant neoliberal paradigm, while the former builds on an international regime of human dignity. Although, as this article argues, international human rights law does not go as far as the species preservation advocates sometimes claim, where it does provide guidance, it should prevail in case of conflict with the international trade or intellectual property regimes. This conclusion is supported both by positive law and by elementary moral considerations.

Thirty years ago, a leading international lawyer predicted that

[the regulation of technological innovation and scientific progress will have to be undertaken in relation to the values of human dignity .... Genetic engineering will soon permit the creation and modeling of men to take place in scientific laboratories. Such breakthroughs have a fundamental bearing on the place of man in the world and should be evaluated by men as beneficial or harmful. The tradition of scientific freedom needs to be reconsidered from the viewpoint of human capacity to put discoveries about forces of nature to constructive social and ecological use.]

He added an allusion to mythology: "We may discover that Olympian gods exhibited a reluctant wisdom by chaining Prometheus—the bearer of progress and technology—to a rock so that he might suffer under public scrutiny." International law provides a tool for tying the biotech Prometheus down. The chain is being

75. Richard Falk, This Endangered Planet: Prospects and Proposals for Human Survival 307 (Random House 1971)
76. Id.
tightened now to restrain his propensity to clone human beings reproductively, but it remains uncertain for the moment which other potential Promethean developments in human genetic manipulation require the restraining effect of international law.