The New Technologies of Human Genetic Modification

A Threshold Challenge for Humanity

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The Center for Genetics and Society is an information and public affairs center committed to encouraging socially responsible governance of the new human genetic and reproductive technologies. Please contact the Center for information on publications, briefings, conferences and other activities.

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EXECUTIVE SUMMARY

- The new human genetic technologies present a threshold challenge for humanity. If used properly they hold great promise for preventing and curing disease. If abused they could open the door to a powerful new eugenics that would objectify human life and undermine the foundations of human civil society.
- These technologies are being developed very rapidly. Neither policy makers nor civil society as a whole have had sufficient opportunity to understand and assess their implications and agree upon policies to prevent their abuse.
- In recent years advocates of the new eugenics have become increasingly vocal and explicit. A strong response from concerned leaders is imperative.
- Bans on the most dangerous eugenic technologies need not impede potentially beneficial medical research and applications.
- The minimal core policies needed to protect our common human future are:
    - national and global bans on the creation of human clones
    - national and global bans on inheritable genetic modification
    - effective, accountable regulation of all other human genetic technologies.
- There is no reason that people of different nations, cultures, religions and philosophies cannot work together in support of the policies needed to protect our common human future.

I

The New Technologies of Human Genetic Modification

A Threshold Challenge for Humanity

CENTER FOR GENETICS AND SOCIETY

We are fast approaching arguably the most consequential technological threshold in all of human history: the ability to alter the genes we pass to our children.

Crossing this threshold would irrevocably change the nature of human life and human society. It would destabilize human biology. It would put into play wholly unprecedented social, psychological and political forces that would feed back upon themselves with impacts quite beyond our ability to foresee, much less control.

Many advocates of the genetic redesign of humanity are promoting a social agenda as well as a technological project. They look forward to the day when parents quite literally assemble their children from genes listed in a catalogue. They celebrate a techno-eugenic future in which our common humanity is lost as genetically enhanced elites increasingly acquire the attributes of separate species.

The implications for individual integrity and autonomy, for family and community life, for social and economic justice and indeed for world peace are chilling. Once humans begin cloning and genetically engineering their children for desired traits we will have crossed a threshold of no return.

The world community is only just beginning to understand the full implications of the new human genetic technologies. There are few civil society institutions, and there is no social or political movement, critically addressing the immense challenges these technologies pose.

We need to move with all deliberate speed to bring the new human genetic technologies within the ambit of responsible societal governance. National and international leaders and civil society constituencies need to inform themselves and join together to build nothing less than a new civilizational commitment to fully engage this threshold challenge.

The Basic Science

Many applications of human genetic technology are benign and hold great potential for treating disease and alleviating suffering. Other applications open the door to a human future more horrific than our worst nightmares. We need to distinguish between these, and support the former and oppose the latter.[1]

[1] See **Section IV-4** for a note on benign and beneficent applications of the new human genetic technologies.

The two technologies of most concern are *human cloning* and *inheritable genetic modification*.

Cloning is the creation of a genetic duplicate of an existing organism. Human cloning starts by creating a human embryo that carries the same set of genes as an existing person. If this embryo is used for research purposes — say, for generating some types of stem cells — the process is called *research cloning*. If instead the embryo is implanted in a woman's uterus and brought to term to produce a child, the process is called *reproductive cloning*.

Genetic modification means changing the genes in a living cell. There are two types of genetic modification: *non-inheritable genetic modification* and *inheritable genetic modification*.[2] Non-inheritable genetic modification changes the genes in cells *other than* egg or sperm cells. If a lung disease is caused by defective lung cell genes, it might be possible to treat the disease by modifying the genes in those lung cells. Such changes are not passed to future children. Applications of this sort are currently in clinical trials, and are generally considered to be socially acceptable.

Inheritable genetic modification (IGM) changes genes in eggs, sperm, or very early embryos. These changes not only affect the child immediately born but are passed down to that child's descendants as well, in perpetuity. This application is by far the more consequential, for it opens the door to the reconfiguration of the human species.[3]

Many people assume that inheritable genetic modification is needed to allow couples to avoid passing on genetic diseases such as Tay Sachs or sickle cell anemia. This is not so. More straightforward means already exist to accomplish this same goal, in all but a very few cases. In the technique known as *pre-implantation screening* couples at risk of passing on a gene-related disease use *in-vitro* fertilization to conceive several zygotes, after which those found to be free of the harmful gene are implanted and brought to term. No modification of genes is required. Although pre-implantation screening can be misused for non-disease traits and would need to be regulated, it is far less dangerous than inheritable genetic modification. Options such as adoption and egg, sperm and embryo donation are also available. Inheritable genetic modification is necessary only if a couple wants to "enhance" a child with genes neither of them carry.

A New Ideology

Advocacy of cloning, inheritable genetic modification and the new eugenics is an integral element of a newly emerging socio-political ideology. This ideology differs from conservative ideologies in its antipathy towards religion and traditional social values, from left-progressive ideologies in its rejection of egalitarian values and social welfare as a public purpose, and from Green ideologies in its enthusiastic advocacy of a technologically reconfigured and transformed natural world. It embraces commitments to science and technology as autonomous endeavors properly exempt from social control, to the priority of market outcomes, and to a political philosophy grounded in social Darwinist views of human nature and society.

[2] The technical terms for non-inheritable and inheritable genetic modification are *somatic* and *germline* genetic modification, respectively.

[3] See **Section IV-3** for a further explanation of basic scientific concepts.

This ideology is gaining acceptance among scientific, high-tech, media and policy elites. A key foundational text is *Remaking Eden: How Cloning and Beyond Will Change the Human Family* by molecular biologist Lee Silver of Princeton University. Silver looks forward to a future in which the health, appearance, personality, cognitive ability, sensory capacity and life-span of our children all become artifacts of genetic modification. Silver acknowledges that the costs of these technologies will limit their widespread adoption, so that over time society will segregate into the "GenRich" and the "Naturals." In Silver's vision of the future:

> "The GenRich – who account for 10 percent of the American population – all carry synthetic genes. . . All aspects of the economy, the media, the entertainment industry, and the knowledge industry are controlled by members of the GenRich class…. Naturals work as low-paid service providers or as laborers…. [Eventually] the GenRich class and the Natural class will become entirely separate species with no ability to cross-breed, and with as much romantic interest in each other as a current human would have for a chimpanzee."

Silver continues:

> "Many think that it is inherently unfair for some people to have access to technologies that can provide advantages while others, less well-off, are forced to depend on chance alone.… [But] American society adheres to the principle that personal liberty and personal fortune are the primary determinants of what individuals are allowed and able to do. Indeed, in a society that values individual freedom above all else, it is hard to find any legitimate basis for restricting the use of repro-genetics…. I will argue [that] the use of reprogenetic technologies is inevitable… . [W]hether we like it or not, the global marketplace will reign supreme."[4]

Silver is hardly alone. Here's James Watson, co-discoverer of the structure of DNA, Nobel laureate and founding director of the Human Genome Project:

> "And the other thing, because no one has the guts to say it, if we could make better human beings by knowing how to add genes, why shouldn't we? What's wrong with it?… Evolution can be just damn cruel, and to say that we've got a perfect genome and there's some sanctity to it? I'd just like to know where that idea comes from. It's utter silliness."[5]

And here's Dr. Gregory Pence, professor of philosophy in the Schools of Medicine and Arts/Humanities at the University of Alabama:

> "[M]any people love their retrievers and their sunny dispositions around children and adults. Could people be chosen in the same way? Would it be so terrible to allow parents to at least aim for a certain type, in the same way that great breeders… try to match a breed of dog to the needs of a family?"[6]

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4 Silver: L. Silver. 1997. *Remaking Eden: How Cloning and Beyond Will Change the Human Family.* (New York: Avon Books), pp. 4-7, 11.

5 Watson: Gregory Stock and John Campbell, eds., 2000. *Engineering the Human Germline.* (New York: Oxford University Press), pp. 79, 85.

6 Pence: G. Pence, 1998. *Who''s Afraid of Human Cloning?* (New York: Roman & Littlefield), p. 168.

And here's noted economist Lester Thurow of MIT:

> "Some will hate it, some will love it, but biotechnology is inevitably leading to a world in which plants, animals and human beings are going to be partly man-made…. Suppose parents could add 30 points to their children's IQ. Wouldn't you want to do it? And if you don't, your child will be the stupidest child in the neighborhood."[7]

Can it get worse than this? Yes. In Germany recently an uproar ensued following statements by philosopher Peter Sloterdijk that the failure of social democracy now leaves human genetic engineering (which he referred to as "Selektion," a word associated with Nazi genocide) as the only means for humanity to improve its lot.[8]

What Is To Be Done?

Recent discussions among concerned scientists, health law experts, human rights leaders, environmentalists, social and economic justice advocates, women's health experts, indigenous peoples advocates and others suggest three policies as the minimal necessary core of a regime addressing the most dangerous applications of the new human genetic technologies. They are:

- National and global bans on reproductive human cloning
- National and global bans on inheritable genetic modification
- Effective, accountable regulation of all other human genetic technologies.

If we are to prevent an escalating and potentially catastrophic spiral of human genetic modification, we will need global bans on both reproductive human cloning and inheritable genetic modification. The bans need to be global to prevent the establishment of eugenic tourism. Further, the bans need to be intended to be permanent. Of course, we can't bind the actions of our descendants, and if they someday decide to repeal these bans they can. But we have the responsibility to make a clear statement, as the human community at this point in history, that we consider human cloning and inheritable genetic modification to be profoundly unacceptable. The proposed global bans are an affirmation among the several generations alive today that we will work to build a human future in which reproductive human cloning and inheritable genetic modification are not done.

Pre-natal and pre-implantation testing, sex selection, human embryo research and other practices have or may have potentially acceptable applications. However, if these are not brought under effective and accountable societal control the danger exists that they could be used in ways that are unacceptable in themselves and that could erode the commitment to forgo reproductive cloning and inheritable genetic modification. A framework needs to be established that would allow humanity as a whole to assess the need for regulation and control of such technologies. Moratoria on some practices may be needed until such assessments are conducted. Further, individual countries need to be able to proscribe applications of these technologies that they find unacceptable.

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[7] Thurow: L. Thurow, 1999. *Creating Wealth: The New Rules for Individuals, Companies and Nations in a Knowledge-Based Economy.* (New York: Harper Collins), p. 33.

[8] See **Section II-1** for additional quotes from advocates of the new eugenics.

We believe that this set of policies is practicable and can attract support from the great majority of the world's countries. All three policies are already in force in one country or another, as described below.

THE CURRENT POLICY LANDSCAPE

Human Cloning

In 1997 scientists at the Roslin Institute in Scotland announced that they had successfully cloned a sheep. This event triggered a worldwide outcry concerning the potential application of this technique to humans. Many countries banned human cloning, and several international bodies – including UNESCO, the Council of Europe, the European Parliament, the G8, and the World Health Assembly – took strong stands against the cloning of human beings. **Section IV-2** shows excerpts from their major texts.

UNESCO adopted a non-binding *Declaration on the Human Genome and Human Rights*, signed by 186 nations. Article 8 of the *Declaration* prohibits "practices which are contrary to human dignity, such as reproductive cloning of human beings." This initiative helped establish legitimacy for the policy of a global ban.

The most authoritative multilateral initiative taken to date to ban human cloning was the Council of Europe's 1998 protocol to its *Convention on Human Rights and Dignity with Regard to Biomedicine*. The protocol prohibits "any intervention seeking to create a human being genetically identical to another human being, whether living or dead." The protocol was opened for signatures on January 12, 1998 in Paris. As of January 2002 it had been signed by 29 of the Council's 41 member states and had been ratified by eleven of these (Greece, Slovakia, Slovenia, Georgia, Spain, Romania, Czech Republic, Portugal, Hungary, Denmark, and San Marino).[9]

Other countries that have passed national legislation banning human cloning include Australia, Austria, Argentina, Brazil, Costa Rica, Germany, India, Israel, Japan, Mexico, Norway, Peru, South Africa, Sweden, Switzerland, Trinidad y Tobago, and the United Kingdom. Some of these laws pertain to human reproductive cloning only, while others also place restrictions on the creation of clonal embryos. As of December 2001 about 30 countries had banned human reproductive cloning. While encouraging, this represents only 16% of all countries and 32% of the world's population.[10]

The announcements in early 2001 by an Italian-American team of scientists of plans to clone a human, and by a Canadian-based sect of their intent to clone a dead child, caused leaders in several countries to ramp up efforts to ban human cloning. Canada's Minister of Health unveiled a comprehensive policy on reproductive and genetic technologies that would outlaw both human cloning and inheritable genetic modification. The Prime Minister of

[9] The other 18 signatories of the *Additional Protocol on the Prohibition of Cloning of Human Beings* include: Croatia, Cyprus, Estonia, Finland, France, Iceland, Italy, Latvia, Lithuania, Luxembourg, Moldova, the Netherlands, Norway, Poland, Sweden, Switzerland, the former Yugoslav Republic of Macedonia, and Turkey. For updates, see: <http://conventions.coe.int/treaty/EN/searchsig.asp?NT=168>

[10] For a complete inventory of national laws on cloning, see <http://www.glphr.org/genetic/genetic.htm>

Japan issued a warning to Japanese scientists against participating in international cloning projects. **Section III-2** contains excerpts of news accounts of these and related developments.

In June 2001 the United States House of Representatives passed a bill banning both reproductive and research cloning. The U.S. Senate is expected to vote on cloning in early 2002. Although support in the U.S. Congress for a ban on reproductive cloning is strong there are sharp disagreements regarding research cloning, and the legislative prospects are uncertain.

Advocates of human reproductive cloning hope to make it happen before a global ban is in place, in the expectation that opposition will weaken in the face of a *fait accompli.* Estimates as to when we could expect the birth of a human clone, if no action is taken to prevent this, range from immediately to five or ten years. If the birth of a clonal child is announced before global bans are in place, opponents of human cloning will need to respond in ways that will build support for policies that will keep such an event from ever happening again.

Inheritable Genetic Modification

As with cloning, the Council of Europe's *Convention on Human Rights and Dignity with Regard to Biomedicine* stands as the most encouraging international initiative to date. Article 13 of the *Convention* states: "An 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 *Convention* has been signed by 30 (73%) of the 41 member states of the Council of Europe and has been ratified directly by the same eleven countries that have ratified the cloning protocol.[11]

Other countries that have passed laws or regulations that explicitly or implicitly proscribe inheritable genetic modification include: Australia, Austria, Costa Rica, Denmark, France, Germany, Hungary, India, Israel, Japan, Norway, Peru, Spain, Sweden, Trinidad y Tobago, and the United Kingdom.[12]

The World Health Organization and World Health Assembly occupy key positions concerning human genetic technology policy. These bodies are global rather than regional and their mandates are operational, not merely advisory. In 1999 a Consultation on Ethical Issues in Genetics, Cloning and Biotechnology was held to help assess future directions for the WHO. The major report prepared as part of this Consultation, *Medical Genetics and Biotechnology: Implications for Public Health*, was notable in calling explicitly for a global ban on inheritable human modification. The WHO has since then established an advisory committee on human genetic technologies. Excerpts from *Medical Genetics and Biotechnology* appear in **Section IV-2.**

The most secure way to ban inheritable genetic modification in any country is to enact national legislation. Treaties, codifications and other multilateral instruments will be needed

[11] For updates to signatories of the *Convention on Human Rights and Dignity with Regard to Biomedicine,* see: <http://conventions.coe.int/treaty/EN/searchsig.asp?NT=164>.

[12] For a complete inventory of national laws on inheritable genetic modification, see <http://www.glphr.org/genetic/genetic.htm>

to secure agreement among all countries to pass such legislation and in that manner help institute a global ban.

Regulation of Other Human Reproductive and Genetic Technologies

Countries differ widely concerning the types of reproductive and genetic technologies they regulate, the procedural rules and the jurisdiction of authority. For regulation to be effective there must be a national authority responsible for licensing all research and commercial facilities involving human embryos and gametes and empowered to revoke licenses when necessary. A frequently cited model for an effective structure of regulation is the Human Fertilization and Embryology Authority (HFEA) in the United Kingdom. See **Section IV-1** for an outline of its structure and function.

The Council of Europe's *Convention* addresses genetic testing, embryology, sex selection and other applications. Article 11 provides that "Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited." Article 12 provides that predictive genetic tests shall be carried out only for health or scientific research purposes. Article 13 states that human embryos shall not be created for research purposes. Article 14 states that techniques may not be used to choose a future child's sex, except where serious hereditary sex-related disease is to be avoided.

TOWARDS AN INTERNATIONAL POLICY REGIME

In late 2001 the United Nations began preparations for negotiations intended to lead to a binding international convention banning human reproductive cloning. This historic effort should be seen as the first step towards a more comprehensive set of policies. Great skill and sensitivity will be needed to craft a convention and a process that allows the world's nations to agree to ban those technologies about which a quick consensus should be possible, while allowing for subsequent consideration of those technologies about which consensus will be more difficult to achieve.

The "Civil Society Deficit"

Given the enormity of what is at stake and the fact that advocates of the new techno-eugenics are hardly coy about their intentions, these developments have attracted remarkably little attention on the part of civil society. Every important issue complex on the world stage today – war and peace, economic growth and equity, social inclusion and exclusion, race and gender equality and the rest – is accompanied by a dense infrastructure of civil society institutions, academic centers, philanthropic programs, NGO coalitions and more. But none of these exist to any considerable extent regarding the social and political issues raised by the new human genetic technologies. Why is this?

One reason is that the most consequential technologies have been developed only within the last few years – there simply hasn't been time enough for people to become aware of what is happening or of the stakes involved. Further, the prospect of "re-designing the human species" is unlike anything that humanity has ever before had to confront. People have trouble taking this notion seriously – it seems fantastical and beyond the limits of what anyone would actually do or that society would allow. In addition, attitudes concerning the

prospect of human genetic modification don't fit neatly along the conventional ideological axes of right/left or conservative/liberal – they track more neatly along a less institutionally expressed libertarian/communitarian axis. All these factors work to impede a prompt response from world leaders and institutions. Initiatives intended to redress this civil society deficit are of the highest importance.

CONCLUSION

Although the work needed to achieve global conventions banning human reproductive cloning and inheritable genetic modification, and establishing adequate regulation of other human genetic technologies, may seem daunting, it is imperative that world leaders affirm the need for such policies now and set the procedures in motion that will make them possible. There is no more important task and there is not much time available. The future of our common humanity is at stake.

II

THE SPECTER OF A NEW EUGENICS

Selected Quotes from Advocates of Human Cloning and Inheritable Genetic Modification

Over the past several years, advocates of a new eugenics have become increasingly vocal and explicit. They anticipate a future based on genetic discrimination and species-altering technologies, a world in which those with financial means routinely select their children's genes.

"**Many people love their retrievers** and their sunny dispositions around children and adults. Could people be chosen in the same way? Would it be so terrible to allow parents to at least aim for a certain type, in the same way that great breeders… try to match a breed of dog to the needs of a family?"

Gregory Pence, professor of philosophy in the Schools of Medicine and Arts/Humanities at the University of Alabama, *Who's Afraid of Human Cloning?* (New York: Roman & Littlefield, 1998, page 168)

"**Some will hate it, some will love it**, but biotechnology is inevitably leading to a world in which plants, animals and human beings are going to be partly man-made…. Suppose parents could add 30 points to their children's IQ. Wouldn't you want to do it? And if you don't, your child will be the stupidest child in the neighborhood."

Lester Thurow, MIT economist, *Creating Wealth: The New Rules for Individuals, Companies and Nations in a Knowledge-Based Economy* (New York: Harper Collins, 1999, page 33)

"**And the other thing, because no one has the guts to say it**: If we could make better human beings by knowing how to add genes, why shouldn't we? What's wrong with it?… Evolution can be just damn cruel, and to say that we've got a perfect genome and there's some sanctity? I'd like to know where that idea comes from, because it's utter silliness."

James Watson shared the Nobel prize for Physiology or Medicine in 1962 for the discovery of the structure of DNA, and served as first Director of the Human Genome Project. Quoted in Gregory Stock and John Campbell, eds. *Engineering the Human Germline* (New York: Oxford University Press, 2000, pages 79, 85)

"**The first century or two of the new millennium** will almost certainly be a golden age for eugenics. Through application of new genetic knowledge and reproductive technologies... the major change will be to mankind itself. [T]echniques...such as...genetic manipulations are not yet efficient enough to be unquestionably suitable in therapeutic and eugenic application for humans. But with the pace of research it is surely only a matter of time, and a short time at that."

Glayde Whitney, "Reproduction Technology for a New Eugenics," paper for The Galton Institute, September 1999. <www.eugenics.net/papers/gw002.html> Whitney wrote the forward to former Ku Klux Klan National Director David Duke's book, *My Awakening: A Path to Racial Understanding*.

"The right to a custom made child is merely the natural extension of our current discourse of reproductive rights. I see no virtue in the role of chance in conception, and great virtue is expanding choice… If women are allowed the 'reproductive right' or 'choice' to choose the father of their child, with his attendant characteristics, then they should be allowed the right to choose the characteristics from a catalog."

James Hughes, bioethics consultant, "Embracing Change with All Four Arms," *Eubios Journal of Asian and International Bioethics* (June 1996, vol. 6 no.4, pp. 94-101). <www.changesurfer.com/Hlth/Genetech.html>

"[In a few hundred years] the GenRich – who account for 10 percent of the American population – [will] all carry synthetic genes…. All aspects of the economy, the media, the entertainment industry, and the knowledge industry [will be] controlled by members of the GenRich class…. Naturals [will] work as low-paid service providers or as laborers…. [Eventually] the GenRich class and the Natural class will become… entirely separate species with no ability to cross-breed, and with as much romantic interest in each other as a current human would have for a chimpanzee."

"[I]n a society that values individual freedom above all else, it is hard to find any legitimate basis for restricting the use of reprogenetics… the use of reprogenetic technologies is inevitable…. There is no doubt about it… whether we like it or not, the global marketplace will reign supreme."

Lee Silver, Professor of Molecular Biology, Ecology and Evolutionary Biology at Princeton University, lectures widely on the social impacts of biotechnology. *Remaking Eden: Cloning and Beyond in a Brave New World* (New York: Avon Books, 1997, pages 4-7, 11)

"'Germline' therapy… will force us to re-examine even the very notion of what it means to be human [as] we become subject to the same process of conscious design that has so dramatically altered the world around us…. Through this technology, we will seize control of our own evolution."

"By the time recipients of even the best engineered chromosome are ready to have children, it will be twenty or thirty years after they themselves were conceived. Their once state-of-the-art artificial chromosome will be hopelessly out-of-date, and they'll want to give their child the latest gene cassettes and artificial chromosomes. It's not so different from upgraded software; they'd want the new release."

Gregory Stock, Director of the Program on Medicine, Technology and Society at UCLA. "The Prospects for Human Germline Engineering," January 1999. <www.heise.de/tp/english/inhalt/co/2621/1.htm>

"[I]f the cost of reprogenetic technology follows the downward path taken by other advanced technologies like computers and electronics, it could become affordable to the majority members of the middle class in Western societies…. And the already wide gap between wealthy and poor nations could widen further and further with each generation until all common heritage is gone. A severed humanity could very well be the ultimate legacy of unfettered global capitalism."

Lee Silver, in an essay published by the Danish Council of Ethics, November 1999. < www.etiskraad.dk/publikationer/genethics/ren.htm>

Examples of Genetic "Enhancements" Proposed by Advocates of Human Cloning and Inheritable Genetic Modification

These lists illustrate the ambitions of those who would use species-altering technologies to, in their words, "seize control of human evolution."

1. From *The Ethics of Human Gene Therapy* by LeRoy Walters and Julie Gage Palmer (New York: Oxford University Press, 1997). Walters and Palmer were appointed to an American Association for the Advancement of Science (AAAS) panel to review the ethics of human genetic technology.

- **Size:** "[T]he germline insertion of a growth hormone gene could enhance the stature of a child who is otherwise destined to be short, or even average in size."
- **Sleep:** "[A] gene for an agent that could reset the circadian clock or reduce the need for sleep would be transferred..."
- **Aging:** "Genetic engineering may ultimately provide the key to prolonged youth."
- **Memory:** "The ability to remember words, names, facts, and experiences is one thing many people might like to improve for themselves and their offspring."
- **Aggression:** "Aggression is often cited as an example of a prime candidate for genetic manipulation, although it is not clear whether the desired change would be an increase or decrease in aggressive tendencies"
- **General cognitive ability:** "A...potential target of genetic enhancement is 'intelligence...'"
- **Moral enhancements:** "[I]t seems likely that additional genetic markers associated with impulsive, aggressive, or violent behavior will be discovered."

2. From a presentation by John Campbell, Prof. of Neurobiology at UCLA, at the Extropy Institute conference *Biotech Futures: Challenges of Life Extension and Genetic Engineering*, Aug. 7, 1999, Berkeley, California. <See www.extropy.org>

- **Currently under consideration:** W. French Anderson's proposal involving "inadvertent" inheritable modification in fetuses.
- **Near-term** (within a generation, i.e., 24 years): prevent arterial disease, counter aging, resist common cold and flu, prevent neurodegeneration, stabilize height and weight, express rare beneficial alleles.
- **Long-term** (several decades; within the lifetimes of young children alive today): adjust personality traits, achieve hyper-intelligence, design body forms, greatly extend life span, introduce traits from other species.

3. From *Remaking Eden: Cloning and Beyond in a Brave New World* by Lee M. Silver (New York: Avon Books, 1997). Lee Silver is professor of molecular biology at Princeton and serves on the faculty of the Woodrow Wilson School of Public Policy.

- Eliminate "[p]redispositions to obesity, diabetes, heart disease, asthma, and various forms of cancer..."
- "[A]ddition of new genes that serve as genetic inoculations against various infectious agents, including the HIV virus..."
- Elimination of "[a]lcohol addiction...along with tendencies toward mental disease and antisocial behavior like extreme aggression."
- Enhance "[v]isual and auditory acuity...to improve artistic potential."
- Addition of "[r]elatively simple animal attributes...includ[ing] the ability to see into the ultraviolet range or the infrared range..."
- "Other possibilities include light-emitting organs (from fireflies and fish), generators of electricity (from eels), and magnetic detection systems (from birds)."
- "Another possible sensory enhancement is four-color vision."
- "[A]s the years go by over the next two centuries, the number and variety of possible genetic extensions to the basic human genome will rise exponentially... Extensions that were once unimaginable will become indispensable...to those parents who are able to afford them."

II-3

Supporters of inheritable genetic modification organized a major public conference in 1998, as reported here in Nature Biotechnology.

"Germline Gene Therapy Contemplated"

Jeffrey Fox, Nature Biotechnology, *May 1998, Volume 16, Number 5.*

A GROUP OF LEADING ACADEMIC scientists met early this spring at the University of California, Los Angeles (UCLA) to consider what technical obstacles need to be overcome before trying germline gene therapy experiments in humans. The participants agree that researchers probably will not be ready for the first clinical trials for at least one to two decades. However, they anticipate rapid technical progress and expect it to help in overcoming current rules in the United States and elsewhere reflecting widely held political and ethical beliefs that deliberate genetic engineering of the human germline should not be attempted.

The research topic on which the day-long UCLA symposium, "Engineering the Human Germline," focused is "not distant anymore, so we need to begin to explore the issue, deepen the dialogue, and make it acceptable," says symposium organizer Gregory Stock, who is director of the UCLA program on science, technology, and society.

Stock and symposium coorganizer John Campbell, a neuroscientist at the UCLA School of Medicine, argue that progress along several fronts such as building human artificial chromosomes, analyzing genomic sequences, and learning how to control gene activity may soon make it easier to engineer human genes at the germline than at the somatic cell level.

Campbell sees germline gene therapy as offering some advantages over current efforts that focus on delivering engineered genes to somatic cells. "I think of the germline as an ideal form of gene therapy, where the same vehicle could be used for delivering every gene that is made, and control becomes the big issue," Campbell says. "A big problem with somatic cell gene therapy is getting genes to the cells where they're needed," he adds.

Meticulous "showcase" studies in model animal systems will be needed before clinical trials are attempted, according to Campbell. "In 20 'cars, we'll have what we need in terms of control so what we do will be reasonably safe and pinpointed before we start fiddling with embryos." He and Stock also say that some safety and ethical concerns can be circumvented by adding controls, such as self- destruct elements, to keep germline genetic additions from being permanently inherited.

The UCLA symposium participants seem to reflect a renewed sense of confidence in gene therapy's technical progress, marking a striking shift since 1995. Then, an expert committee, appointed by NIH (Bethesda, MD) director Harold Varmus and cochaired by Stuart Orkin of Harvard Medical School (Boston) and Arno Motulsky of the University of Washington (Seattle), delivered a report criticizing scientists at companies and universities who work in this field, in part for creating false expectations about the progress they had made (*Bio/Technology* **14**:14, 1996). That report urged a "greater focus on basic research," and reminded investigators that, even though prospects for this research "are great, clinical efficacy has not been definitively demonstrated," and that "significant problems remain in all basic aspects of gene therapy."s-based, therapeutic clinical trials have been undertaken, according to the database maintained by the NIH Office of Recombinant DNA Activities (ORDA). Although no unusual safety concerns have been reported, results indicating unequivocal therapeutic successes have also not yet been reported for any of these somatic cell-directed, gene-transfer clinical tests.

So far, no researchers have come forward with a scheme to test gene transfers in humans at the germline level. Indeed, because the topic of germline gene therapy has been taboo, technical progress now being made in the research areas that underpin it could lead to "great dangers if [clinical proposals] are sprung unexpectedly"

on the public, Stock says. He does not want to see germline therapy treated the same as human cloning was throughout much of 1997, "where people jumped to legislate research restrictions" even though no one was proposing tests of such procedures on human cells.

However, germline procedures already are subject to restrictions. Canada and many countries in Europe are "quite opposed to germline interventions, but in the United States, the discussion has been moving to whether it would be all right to do this in principle," says Leroy Walters, director of the Center for Bioethics at Georgetown University (Washington, DC) and former chair of the NIH Recombinant DNA Advisory Committee. He adds, "The key question is, if the technical means are well developed, whether the intervention is intended to prevent disease."

Meanwhile, US regulatory officials insist on rigorous testing to ensure that transferred genetic materials are not inadvertently introduced into germline tissues during somatic gene therapy clinical and preclinical tests. For instance, last year officials at the US Food and Drug Administration (FDA; Rockville, MD) told gene therapy researchers at the University of Pennsylvania (Philadelphia) 1 prove that the vectors they plan to use in clinical protocols do not deliver and integrate genes into mouse gonadal tissues, says former ORDA Director Nelson Wivel, who is now part of the University of Pennsylvania gene therapy research team.

"We loaded high amounts of the vector to get it into reproductive tissues of mice," Wivel says. PCR tests indicate that some of the over loaded vector material duly appears in mouse germline tissues, but other tests prove that the transferred genetic material does not become integrated there and is not passed to offspring mice, he says.

Although ORDA officials have asked gene therapy researchers to review clinical protocols for evidence of any germline transfers among human subjects, there is "not much definitive data," Wivel says. Available anecdotal findings provide "no evidence for integrated DNA in germline tissues" among those human subjects.

<http://www.nature.com/nbt/wilma/v16n5.894052177.html>

II-4

European scientists and policy makers have warned of the dangers of germline engineering, as seen in these letters to Nature.

"Problems of Germline Therapy"

Letters by Anne McLaren and Jonathan Ewbank, Nature, *April 16, 1998*

Sir—You recently published a full-page report of a Californian symposium on germline gene therapy, and a leading article, without a single mention of preimplantation genetic diagnosis.

If a couple are at risk of having a child with a serious genetic disease, it is now possible for them to have their embryos screened at the eight-cell stage, after *in vitro* fertilization, to ensure that only unaffected embryos are transferred to the uterus. Only in the very rare cases where both partners are sufferers from a recessive condition that allows survival to reproductive age, such as cystic fibrosis, will no unaffected embryos be generated. As 10-20 embryos could be produced from a single egg recovery, it would not be difficult also to avoid the birth of carriers if that was desired.

Most couples would surely prefer to avoid the transfer of affected embryos, rather than seeking to tamper with their DNA at such an early stage, with possibly unpredictable consequences. Leroy Hood, chair of molecular biotechnology at the University of Washington, said: "We are using exactly the same kinds of technologies that evolution does". For those who know anything about evolution and its many failures, this is hardly a strong recommendation.

James Watson is reported as saying: "Scientists should proceed unhindered towards germline engineering". Either he has forgotten that the simpler and safer technique of preimplantation genetic diagnosis, already in clinical use, renders germline gene therapy for genetic diseases virtually pointless, or it is germline engineering for genetic enhancement towards which he wishes to proceed unhindered?

If it is the latter, he should say so. How about it, Jim?

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Sir— One statement in your recent leading article about the consequences of germline gene therapy[1] is unfortunately familiar: "Our first task should be to take a long, hard look at [what] is likely to be involved — both scientifically and ethically". This recalls "Government, religious, civic, and scientific leaders should encourage widespread public discussion of the pros and cons of germ line gene therapy"[2] and, from a Commentary in *Nature*, "timely ethical discussion of this issue, before germline gene therapy in humans is technically feasible, may assist future policy-makers in their deliberations."[3]

Indeed, this apparent concern was voiced in one of the first official inquiries into the subject: "The novelty of gene splicing ought not to erect any automatic impediment to its use but rather should provoke thoughtful analysis. Especially close scrutiny is appropriate for any procedures that would create inheritable genetic changes".[4]

As technical advances make germline gene therapy an even more imminent possibility, one can ask, what has happened in the intervening 16 years? Why has this debate not reached a broader audience? And when will the debate spread beyond the offensive pronouncements of James Watson, who, when once asked if he feared that genetic engineering could be used for 'positive eugenic' ends, replied, "It's not much fun being around dumb people"?

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1. Nature 392, 315 & 317 (1998).
2. Institute of Medicine, National Academy of Science. *Human Gene Therapy* (Harvard University Press, 1988).
3. Walters, L. Nature 320, 225-227 (1986).
4. US President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research. *Splicing Life* (US Government Printing Office, Washington, DC, November 1982).

<http://www.nature.com/cgi-taf/dynapage.taf?file=/nature/journal/v392/n6677/full/392645a0_fs.html>

II-5

This Associated Press article illustrates the way in which inheritable genetic modification is being portrayed as both inevitable and desirable.

"Designing Baby: Scientists on Verge of Manipulating Human DNA"

Daniel Q. Haney, *Associated Press, March 5, 2000*

SUPPOSE PARENTS-TO-BE COULD guarantee their children will grow up to be unusually healthy. Or extra smart. Or maybe just a little better looking than mom and dad.

Sound pretty good?

Now, suppose that guarantee requires a level of planning that goes way beyond the usual prenatal care. Suppose it requires some fiddling with the future kids' DNA, adding a few genes here and there to slow down aging or rev up the brain circuitry or lock in resistance to viruses.

Still sound good?

Even if your answer is a definite no, some scientists believe many parents will find this a very attractive option. For now, the choice is science fiction – but just barely so.

The time is coming, many scientists say, when parents will pick their children's genes.

From the menu of possibilities, parents might select genes to make their babies resist common diseases and infections, things like cancer, AIDS, heart attacks and Alzheimer's disease. Maybe they would like their children to have fabulous memories or winning personalities or a talent for playing the piano.

A couple of extra inches of height and a thick head of hair could be nice, too.

To hear these scientists talk, all of this and much more will be possible in the not-so-distant future. "There's nothing beyond tinkering," says Lee Silver, a Princeton biologist.

Not this year or next, probably, and maybe not in the next 10 or even 20 years. But these scientists predict the amazing breakthroughs in genetically engineering lab mice and farm critters will eventually be applied to the animals at the top of the food chain.

"It's not a question of 'if' but 'when' and 'how' this will occur," says Gregory Stock, head of the Program on Medicine, Technology and Society at UCLA's School of Medicine.

Stock and Silver are visionaries in their field, men who enjoy painting the big picture of an over-the-horizon science called human germline engineering. Germline refers to the sperm and egg. These scientists are talking about changing the genetic makeup of a person-to-be at the moment of conception.

Something like this: Insert block of new genes into a freshly fertilized egg. The one cell becomes two, then four, then eight. Each new version carries the extra information. In nine months, a baby is born. Every cell in his or her body contains the extra genes.

The child grows up. Marries. Passes the extra genes on to the next generation of babies. And they on to theirs. And so on. Or maybe not. The unsettling prospect of handing these genetic fixes down the generations is just one of the many controversies of this obviously hot-button field.

"The reason people are fascinated by this whole area is that it will challenge our fundamental thinking about who we are and what it means to be human," says Stock. "We are talking about remaking human biology."

But what part of biology to remake first? Typically the answer is to reduce our tendency to get sick.

While personal habits and medical care play an obvious role in health, inheriting good genes gives some folks a powerful edge. Scientists already know some of the combinations of genes that help people resist some big-ticket

illnesses. So one goal of human germline engineering could be to help the genetically less fortunate share these built-in health advantages.

For instance, the risk of heart disease depends in part on the levels of HDL, the good cholesterol. More is clearly better. In the human body, a gene called ap0-A1 makes a major piece of HDL. The same is true in mice, whose biology, scientists love to point out, is not so different from ours.

"It's possible in mice to dial in virtually any HDL level you want by introducing more copies of this gene," says Dr. R. Sanders Williams, a cardiologist at the University of Texas Southwestern Medical Center.

So why not add some extra apO-A1 genes to one-cell persons-to-be and reduce their chance of dying from humanity's leading killer?

Perhaps resistance to the AIDS virus would also appeal to gene-shopping parents. Scientists can imagine a way to do that. Those who are born with two defective copies of a gene called CCR5 can escape HIV infection despite thousands or risky sexual encounters. The reason: CCR5 makes a protein that the AIDS virus locks onto when it invades white blood cells. So, no CCR5 protein on the surface of a cell – no infection.

Of course, there is no reason to stop with disease protection, the visionaries say. Many genetic "enhancements," as they are called, can also be imagined.

One obvious enhancement is extra brain power. At Princeton, scientists have already created mice – nicknamed "Doogie" after TV's physician prodigy – that are rodent geniuses. They learn faster, remember longer and adapt to changes better than any ordinary mouse.

What makes these mice unique is an extra copy of a gene that produces a brain chemical called NR2B. This stuff boosts the cellular switches that help the brain store associations. (When you remember the name that goes with a face, that's an association.) While a human brain is more complex than a mouse's, the basic machinery of learning may be pretty much the same in both.

Even selecting a child's personality in advance might be possible. Experts believe that half of people's personality traits are hard-wired by their genes. Of course, lots of genes combine to create any individual's melange of quirks and temperament. So building a child with, say, David Letterman wit, Mother Theresa compassion and Warren Buffett business sense may not be real easy at first.

The field's visionaries toss off sweep-of-the-hand solutions for this and many other problems and predict the science fiction will become science within a generation.

"I think it could occur 10 years from whenever we decide it should," says John Campbell, a UCLA neurobiologist. "It depends a lot on motivation. It won't be limited by science."

<http://research.mednet.ucla.edu/pmts/aprstock.htm>

II-6

Rather than raising alarm at the prospect of a new commercial eugenics, some scientists appear willing to accept it and work to make it safe and reliable, as suggested by this presentation for the Advanced Technology Program of the National Institute of Standards and Technology.

EXCERPT FROM

"Human Germline Engineering – The Prospects for Commercial Development"

Gregory Stock and John Campbell

Advanced Technology Program of the National Institute of Standards and Technology
Electronic Workshop Presentation: Paper No. 18

In discussions of cloning and germline modification of animals, it's easy to pretend that human manipulations can be ignored. But it seems virtually certain that as these technologies evolve, their focus will swing back towards our own selves. The real question is not whether they will be applied to humans, but when, how, and to what extent.

Some people maintain that human manipulation is inevitable because what can be done will be done. But what can be done often is not done, so why should this technology be more likely than say a nuclear power plant in downtown New York? The answer lies in the nature of advanced reproductive technologies like germline engineering and cloning. Judging by today's rapid progress, they ultimately will be easy enough, safe enough, and cheap enough to be feasible in countless laboratories worldwide. Thus even if illegal and morally opposed by most people in most countries, they would become as uncontrollable as euthanasia or abortion.

Human cloning provokes considerable debate, but human germline engineering is more significant because its implications ultimately will be more profound. However strange it may seem to clone a delayed identical twin, the act hardly challenges our basic concepts about what it means to be human. But human germline engineering — poised to make our very biology the object of conscious design — is a step so big in humanity's reach to control its own evolution that no one can say where it will lead.

Two things will be necessary before human germline engineering can occur broadly:

- A safe, reliable way of delivering genetic changes to a human embryo, and
- Genetic modifications so compelling that large numbers of parents will want them.

Until both exist an occasional rogue attempt to clone or genetically modify a child may occur, but responsible physicians will not apply this emerging technology to humans.

Interestingly, the above two developments may be much nearer than many imagine....

The basic discoveries that make human germline manipulations possible are likely to emerge not from controversial experiments on human embryos, but from mainstream research on mice, sheep, cows, primates, and human somatic cells. Work on human embryos will probably be needed only to refine techniques proven elsewhere...

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Full document available at <http://research.mednet.ucla.edu/pmts/Stockatp.htm>

II-7

Although "post-humanism" and "transhumanism" may appear to most as bizarre ideologies, they are attracting sophisticated and committed proponents, as seen in this paper.

EXCERPTS FROM

"The Politics of Transhumanism"

James J. Hughes, Ph.D., Public Policy Studies

Trinity College, Hartford, Connecticut

Prepared for the 2001 Annual Meeting of the Society for Social Studies of Science
Cambridge, MA, November 1-4, 2001

Abstract

"Contemporary transhumanism has grown out of white, male, affluent, American Internet culture, and its political perspective has generally been a militant version of the libertarianism typical of that culture. Nonetheless transhumanists are becoming more diverse, with some building a broad liberal democratic philosophic foundation in the World Transhumanist Association. The essay also discusses the emergence of neo-Nazi and radical democratic transhumanism. For transhumanism to achieve its goals it needs to distance itself from its anarcho-capitalist roots and its authoritarian mutations by clarifying its commitments to liberal democratic institutions, values and public policies. By embracing political engagement and the use of government to address equity, safety and efficacy concerns about transhuman technologies, transhumanists are in a better position to attract a larger, broader audience."

Excerpts:

"In this paper I will briefly discuss the political flavors of transhumanism that have developed in the last dozen years, including extropian libertarianism, the liberal democratic World Transhumanist Association, neo-Nazi transhumanism, and radical democratic transhumanism. In my closing remarks I will suggest ways that a broader democratic transhumanism may take shape that would have a better chance of attracting a mass following and securing a political space for the kinds of human self-improvement that the transhumanists envision."

"In the last couple of years the neo-Luddite movement has grown in coordination and political visibility, from movements against gene-mod food, cloning and stem cells, to President Bush's appointment of staunch bio-conservative ethicist Leon Kass as his chief bioethics advisor. Despite faith in the inevitability of the millennium, the neo-Luddites have sufficiently alarmed the extropians that in 2001 Natasha Vita-More announced the creation of the Progress Action Coalition ("Pro-Act"), an extropian political action committee. The group's announced intention is to build a coalition of groups to defend high technology against the Luddites."

"The group is still being set up, but the set of scientific and cultural members, supporters and fellow-travelers that the extropians have collected could be leveraged for considerable political effect. Engaging in actual political campaigns to defeat anti-cloning or anti-stem cells bills would inevitably force the extropians to grapple with partisan politics and the ways in which the state actively supports science, further attenuating their anarchist purity."

"In response to a question about how post-humans will treat humans, the [World Transhumanist Association] notes 'it could help if we continue to build stable democratic traditions and constitutions, ideally expanding the rule of law to the international plane as well as the national.' (Bostrom et al., 1999) here the transhumanists are anticipating the need to build political and cultural solidarity between humans and post-humans, to minimize conflicts, and to have global police institutions that can protect humans from post-humans and vice versa."

Full document at: <http://www.changesurfer.com/Acad/TranshumPolitics.htm>

III

THE NEED FOR A CIVIL SOCIETY RESPONSE

Selected Quotes from Those Calling for Bans on Human Cloning and Inheritable Genetic Modification

Thoughtful observers and civil society leaders have begun to speak out against species-altering technologies and a new eugenics.

"[G]erm-line genetic alteration [poses] many risks and potential harms, without any clear benefit to any individual. It… jeopardizes, rather than protects, those who are vulnerable…. Genetic enhancement raises the prospect of a society where… people are treated as things that can be changed according to someone else's notions of human perfection."

Canadian Royal Commission on New Reproductive Technologies, *Handle with Care*, 1994 (excerpted in *Human Gene Therapy*, Vol. 5, pages 612-613)

"Germ-line modification is not needed in order to save the lives or alleviate suffering of existing people…. The cultural impact of treating humans as biologically perfectible artifacts would be entirely negative."

Council for Responsible Genetics. "Position Paper on Human Germ Line Manipulation," 1992

"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."

Gina Maranto, science writer. *Quest for Perfection: The Drive to Breed Better Human Beings* (New York: Scribner, 1996, page 278)

"Equally important are the hazards of germline engineering of human beings. In addition to creating a new, free market form of eugenics, with catastrophic consequences for society, such technologies turn children into consumer products, undermining their basic human right to self-determination…"

From a letter to the World Health Assembly calling for a global convention on the new human genetic technologies, , May 15, 2001, signed by 70 international experts and activists from 14 countries, including Bolivia, Brazil, India, Sri Lanka, Poland, Nepal, Italy, Bolivia and Switzerland.

"What can happen when the technology used in support of genetic thinking is not the crude technology of shackles and slave ships, of showers that pour lethal gas and of mass ovens, or even the technology of surgical sterilization, but the fabulous, fantastic, extraordinary technology of the new genetics itself? My children will not be led to genetic technology in chains and shackles, or crowded into cattle cars. It will be offered to them."

Barbara Katz Rothman, sociologist, City University of New York, "A Sociological Skeptic in the Brave New World," *Gender & Society* (vol. 12 no. 5, October 1998)

"[W]e have finally reached a point where scientists have proved dispositively that race is not genetic but an irrational social construct—well, suddenly there's also the ability to alter the human germline in ways that may, in fact, create new classes of genetic characteristics resembling what we had only imagined heretofore as racial difference.**"**

Patricia J. Williams, "Dust and Destiny," *The Nation*, July 17, 2000

"[Cloning a dying child] should not be permitted. Not only does this encourage the parents to produce one child in the image of another, it also encourages all of us to view children as interchangeable commodities. The death of a child thus need no longer be a singular human tragedy, but rather an opportunity to try to duplicate the no longer priceless deceased child.**"**

George J. Annas, Boston University School of Public Health, *Some Choice: Law, Medicine, and the Market* (New York: Oxford University Press, 1998, pages 12-13)

"[U]nless we mobilize the courage to look foursquare at the full human meaning of our new enterprise in biogenetic technology and engineering, we are doomed to become its creatures if not its slaves…. [I]t is not too late… to become aware of the dangers, not just to privacy or insurability, but to our very humanity. So aware, we might be better able to defend the increasingly beleaguered vestiges and principles of our human dignity, even as we continue to reap the considerable benefits that genetic technology will inevitably provide.**"**

Leon R. Kass, bioethicist, University of Chicago, "The Moral Meaning of Genetic Technology," *Commentary*, September 1999

"[W]e can easily imagine an arms race developing over GNR [genetics, nanotechnology, and robotics] technologies, as it did with the NBC [nuclear, chemical, and biological] technologies in the 20th century…. This time… we aren't in a war… we are driven, instead, by our habits, our desires, our economic system, and our competitive need to know.**"**

Bill Joy, Chief Scientist and Co-founder, Sun Microsystems, "Why the Future Doesn't Need Us," *Wired*, April 2000

"[The] dominant view of liberty reserves most of its protection only for the most privileged members of society....Reproductive freedom is a matter of social justice....[P]rocreation's special status stems as much from its role in social structure and political relations as from its meaning to individuals.**"**

Dorothy Roberts, J.D., *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Pantheon Books, 1997).

"Germline manipulation opens up, for the first time in human history, the possibility of consciously designing human beings…. [T]he world is not a safe enough place to let this particular genie out of its bottle, and it would be irresponsible in the extreme to do so.**"**

David King, Editor, *Human Genetics Alert* (formerly *GenEthics News*), London.
"No to Genetic Engineering of Humans," < www.hgalert.org >

International Reactions to the Push for Human Cloning and Inheritable Genetic Modification

Following the January 2001 announcement by Severino Antinori, Panos Zavos and others of plans to begin cloning human beings, world leaders reacted by calling for global bans.

FEBRUARY 2 - Japan Issues Warning To Scientists On Human Cloning Project. (AP)–Prime Minister Yoshiro Mori instructed his science minister Friday to take steps to prevent Japanese researchers and doctors from participating in an international project to clone human beings.

FEBRUARY 4 - Australian Scientist Horrified at Human Clone Plan. Two international medical scientists are trying to lure Victoria's top reproductive scientist, Alan Trounson, into a taboo-busting project aimed at cloning the first human being. Trounson's reply: "I'm sure they would like anybody who would add credibility to the team to go on it. No way. No way!" <www.theage.com.au/news/2001/02/04/FFXPQ246QIC.html>

FEBRUARY 8 - Romania Bans Human Cloning. (Monitorul Online) Yesterday, deputies decided to forbid human cloning in Romania, by passing a draft bill which ratified the European Convention concerning the protection of the human rights and that of the human being's dignity.

FEBRUARY 10 - French President Calls for Ban on Human Cloning. French President Jacques Chirac criticized Britain's decision last month to let scientists clone human embryos for medical research, and called for an international ban on the practice. Therapeutic cloning, Chirac said, "leads to the creation of embryos for the purposes of research and the production of cells and, in spite of the ban, makes reproductive cloning practically possible…" <www.newsmax.com/archives/articles/2001/2/10/103138.shtml>

MARCH 1 - Council of Europe Ban on Human Cloning Takes Effect. The Council of Europe's protocol against human cloning, the first binding international ban, took effect on March 1 when a fifth nation ratified it. Twenty-four of the 41 Council of Europe states have signed the protocol. <www.centraleurope.com/romaniatoday/local-press/monitorul.php3?id=285444>

MARCH 8 - Human Cloning Illegal in China. The Xinhua News Agency reports that a member of the Chinese People's Political Consultative Conference National Committee stated that human cloning is not allowed in China. <library.northernlight.com/FA2001030842000003 6.html?cb3D0&dxg3D100= 6&sc3D0>

MARCH 10 - Prominent Italians Against Human Cloning. (AP) - A day after researchers meeting in Rome vowed to clone babies, an Italian lawmaker condemned them as "Frankenstein doctors" and urged parliament to ratify an international pact banning human cloning. A prominent cardinal also condemned the project, as did the head of Italy's national committee on bioethics.
<dailynews.yahoo.com/h/ap/20010310/sc/human_cloning_1.html>

MARCH 12 - British, Australian, and Italian Medical Authorities Condemn Human Cloning. Antinori and Zavos were condemned by Britain's Human Fertilisation and Embryology Authority and by the Australian Medical Association. The Italian medical association warned that any member who tries to clone a human risks expulsion and loss of the right to practice medicine.
<salon.com/mwt/wire/2001/03/12/cloning/index.html>

MARCH 13 - The Cypriot government said it would not permit human cloning after Antinori identified Cyprus as a possible locale for his project. <www.ekathimerini.com/news/content.asp?id=74950>

MARCH 13 - Kenyans Join Condemnation of Human Cloning. Archbishop Ndingi Mwana A'Nzeki of Nairobi, the vice chancellor of Kenyatta University, and Muslims leaders also joined criticism of human cloning.

MARCH 13 - German and Filipino Bishops Oppose Human Cloning. Roman Catholic bishops in both Germany and the Philippines have condemned all forms of human cloning, either for reproductive or so-called therapeutic purposes.
<www.zenit.org/english/archive/0103/ZE010311.htm#3389>

MARCH 30 - Prominent Scientists Oppose Cloning. Rudolph Jaenisch and Ian Wilmut, head of the team that created the first mammal cloned from an adult, opposed human cloning in a letter to *Science* magazine.
<www.sciencemag.org/cgi/content/full/291/5513/2552>

APRIL 12 - Schroder Speaks Against Human Genetic Modification. German Chancellor Gerhard Schroder recently said, "We agree on what we do not want: the cloned, optimized, genetically selected human being." (*New York Times*, "Horror Expressed in Germany Over Dutch Euthanasia")

APRIL 19 - Britain to Ban Human Cloning. The government announced that it would introduce a legislative ban on human cloning, which is already disallowed under the British regulatory framework.
<news.bbc.co.uk/hi/english/health/newsid_1285000/1285151.stm>

MAY 3 - Canada Introduces Legislation on Genetic and Reproductive Technologies. The Canadian Health Minister submitted to the House of Commons legislation that would ban human cloning; germline modification; and commercialization of human eggs, sperm, embryos or surrogacy arrangements. The proposed legislation would also set up a regulatory framework to control other uses of reproductive technology.

NOVEMBER 30 - Lagos, Nigeria University VC Calls for Measures Against Human Cloning. University of Port Harcourt vice-chancellor, Prof. Nimi Briggs, has called for urgent measures to regulate research on human cloning.

III-3

Health and Human Rights Leaders Call for International Ban on Cloning and Species-Altering Procedures

Report on the conference *Beyond Cloning: Protecting Humanity from Species-Altering Procedures,* held at Boston University, Sept. 21-22, 2001.

Leading health law experts, advocates for human rights and social justice, environmentalists, women's health leaders and others gathered at Boston University September 21-22 for *Beyond Cloning: Protecting Humanity from Species-Altering Procedures*. Conference organizers and speakers called for a global ban on genetic procedures that fundamentally change the nature of the human species.

"Uncontrolled use of the new genetic technologies risks setting us on a dehumanizing road to genetic genocide," said George Annas, professor and chair of Boston University's Health Law Department, one of the conference sponsors. "We need a comprehensive global treaty that bans the most dangerous genetic technologies while allowing beneficial medical applications to proceed."

More than 140 participants discussed the ethical, legal, and social challenges raised by human genetic technologies; the inadequacy of existing controls; possible provisions of a new global treaty; and political strategies for its adoption.

The envisioned global accord would ban the creation of human clones and the modification of inheritable genes, and provide for regulations to ensure that other new human genetic and reproductive technologies are used in ways that benefit rather than harm human life and society.

Conference organizers noted that many governments, including most recently those of France and Germany, have called on the United Nations to initiate discussions intended to lead to a global treaty, and that for such an effort to succeed a broad civil society initiative, including non-governmental organizations, is needed.

Leading participants in the conference included advocates of women's health and reproductive choice, disability rights, indigenous peoples rights, and environmental protection.

Proponents of a global ban plan the publication of a report outlining the need for such an initiative; further discussions with a wide range of scientific, legal, health, human rights, environmental and political leaders about ways to put such a proposal on the international agenda; and an international conference at a venue outside North America.

Key points made by conference speakers follow:

- **Lori Andrews**, Distinguished Professor of Law and Director of the Institute of Science, Law and Technology, Chicago-Kent College of Law, argued that bans, not moratoria, are needed for the most dangerous genetic technologies.

- **George Annas**, Professor and Chair, Health Law Department, Boston University School of Public Health and Co-founder, Global Lawyers and Physicians, argued that "individuals, countries, or corporations" have no rights to genetically alter the human species.
- **Patricia Baird**, University Distinguished Professor, Department of Medical Genetics, University of British Columbia and former Chair, Canadian Royal Commission on the New Reproductive Technologies, reviewed the public consultation process that has led Canada to propose national legislation that would regulate the new technologies, and ban cloning and inheritable genetic modification.
- **Brent Blackwelder**, President, Friends of the Earth, affirmed that the genetic modification of the human species and of the processes of the natural world in general should be strongly opposed by environmentalists.
- **Alexander Capron**, Director, Pacific Center for Health Policy and Ethics, University of Southern California, made a strong case for a moratorium on the creation of clonal embryos for research purposes.
- **Michael Dorsey**, Sierra Club National Board of Directors and Thurgood Marshall Fellow, Dartmouth College, emphasized the necessity for early participation by the global south in any international treaty.
- **Leonard Glantz**, Associate Dean and Health Law Professor, Boston University School of Public Health, challenged participants to articulate more clearly why they oppose species-altering technologies.
- **Michael Grodin**, Professor of Health Law, Boston University, and co-founder, Global Lawyers and Physicians, demonstrated the inadequacy of existing regulations and structures to control species-altering genetic technologies.
- **Debra Harry**, Executive Director, Indigenous Peoples Council on Biocolonialism, argued that indigenous peoples need to be involved in the early stages of any proposed treaties.
- **Richard Hayes**, Executive Director, Center for Genetics and Society, emphasized the urgent need to build a broad social movement, including both professional organizations and mass-based popular organizations, to counter the push towards a techno-eugenic future.
- **Andrew Imparato**, President, American Association of People with Disabilities, recalled the history of eugenicist targeting of people with disabilities, and criticized the exploitative use of images of disabled people to motivate opposition to harmful technologies.
- **Rosario Isasi**, Health Law and Bioethics Fellow, Boston University School of Public Health, and Global Lawyers and Physicians (Peru), demonstrated a new interactive web site that displays national and international policies on human cloning and inheritable genetic modification. See <www.glphr.org/genetic/genetic.htm>.
- **Stephen Marks**, Director, Francois-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health, detailed existing international treaties and proclamations that establish grounds for constraining species altering technologies.

- **Maxwell Mehlman**, Professor of Law and Director, Law-Medicine Center, Case-Western Reserve University, noted that although a global treaty would face many obstacles, it appears to be an appropriate solution to the dangers posed by the new technologies.
- **Stuart Newman**, Professor of Cell Biology and Anatomy, New York Medical College, and Board Member, Council for Responsible Genetics, argued that human cloning and inheritable genetic modification are inherently unsafe, and that it would be impossible to "get there from here" without the unacceptable use of human lives as experiments.
- **Judy Norsigian**, Executive Director and Co-Founder, Boston Women's Health Book Collective, emphasized the special impact that new genetic and reproductive technologies have on women and children.
- **Evelyne Shuster**, Human Rights and Ethics Program, and Adjunct Associate Professor of Philosophy and Psychiatry, University of Pennsylvania, noted that the rhetorical categories used to describe the new genetic technologies bias us towards their acceptance.
- **Susannah Sirkin**, Deputy Director, Physicians for Human Rights, recounted the strategies and tactics used by Physicians for Human Rights to win a global treaty banning landmines.
- **Ann Snyder**, Executive Director, Ethics, Law and Biotechnology Society, Harvard Law School, spoke as a member of the Harvard student community. She called for more dialogue before making potentially irreversible decisions.

The Conference was co-sponsored by the Boston University Health Law department, the Center for Genetics and Society, the Illinois Institute for Science, Law and Technology, Global Lawyers and Physicians, and the Harvard University Ethics, Legal and Biotechnology Society. Report was prepared by the Center for Genetics and Society.

Beyond Cloning website: <www.bumc.bu.edu/www/sph/lw/website/index.htm>

This important speech addresses the profound dangers of the new human genetic technologies

"Genism, Racism, and the Prospect of Genetic Genocide"

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Prepared for presentation at UNESCO 21st Century Talks: The New Aspects of Racism in the Age of Globalization and the Gene Revolution at the *World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance*, Durban, South Africa, September 3, 2001.

I greatly appreciate the opportunity to speak to you on the topic of "Genism, Racism, and the Prospect of Genetic Genocide" in conjunction with the *World Conference against Racism*. I think there is little doubt that the 21st century will be the century of human genetics. New genetic technologies have the potential not only to change what we can do to ourselves and each other, but more importantly, to change the very way we see ourselves and each other.

Our superficial perceptions of each other have often fostered racism in the past. Simply defined, racism is "the theory that distinctive human characteristics and abilities are determined by race." The hunt for genes, especially in groups identified by racial classifications, could lead to "genism" (a term not yet officially recognized, but one I would define as the theory that distinctive human characteristics and abilities are determined by genes) based on DNA sequence characteristics with resulting discrimination as pernicious as racism

A second consequence of the new genetics will be a temptation to use our new powers to transform ourselves by attempting to create a "better baby" or even whole new categories of posthumans, eventualities warned of in Huxley's Brave New World. Huxley's world relied on conditioning to enable the enslavement of categorically "inferior" humans by their genetic "superiors." A more likely outcome is genetic genocide: the elimination of the new human by the old, or vice-versa. Let me briefly explain each of these dangers and suggest ways we might avoid them.

Genetic Universality or Genism?

The great hope of genomics is that it will scientifically demonstrate that humans are all essentially the same, and that this demonstration will lead us to exchange our penchant for making distinctions among humans for a view that all humans are essentially the same. And genomics has already accomplished the science part.

After the draft of the human genome was announced last summer, for example, Chris Stinger of London's Natural History Museum observed, "We are all Africans under the skin." The same point was made by other geneticists in different words, one noting that "race is only skin deep" and another, that "there is nothing scientific about race: no genes of

any sort pattern along racial lines." Craig Venter, the leader of the private genome mapping effort, concluded:

> Race is a social concept, not a scientific one. We all evolved in the last 100,000 years from the same small number of tribes that migrated out of Africa and colonized the world.

This is all to the good, and geneticists deserve praise for getting this antiracism message out to the public. Unfortunately, the message of genetics, while undercutting racism can simultaneously invigorate its evil brother, genism. This is how it works. Eric Lander, the genomics leader from the Massachusetts Institute of Technology has noted that although we are all 99.9% genetically identical, that .1% of difference is made up of 3 million spelling variations in our genomes. Each of these genetic variations could be used as a pseudoscientific basis for discrimination based on genetic endowment.

Genome leaders have recognized this, and have called for legislation to prohibit genetic discrimination in employment, health insurance, life insurance, and disability insurance. These are not the only arenas of discrimination that should concern us. Most important are the ways in which knowledge of our genomes will affect how we view our own life's possibilities, and even how our friends and families view us. The geneticists have said that understanding the genomic code will enable us to understand life at the molecular level. But we do not live life on the molecular (or atomic or subatomic) level, but as full-bodied human beings. It is this reductionistic view of humans as a collection of genes that is at the core of genism.

An example is provided by the now defunct "Human Genome Diversity Project" which sought to collect DNA samples form some 700 of the world's isolated ethnic groups, sometimes referred to as the world's "vanishing tribes." In the project's view, it was more important that science seize the opportunity to collect DNA from these peoples than that any action be taken to actually help the peoples themselves. The indigenous peoples around the world properly and forcefully rejected this project, and insisted that their human rights be placed above this dubious and reductionistic project.

It is true that "we are all Africans under the skin." It is also true, however, that if we decide to search for genetic differences in the .1% of our DNA that is different, we will find them and use them against each other. Philosopher Eric Juengst put it well:

> No matter how great the potential of population genomics to show our interconnections, if it begins by describing our differences it will inevitably produce scientific wedges to hammer into the social cracks that already divide us.

Preventing genism from taking over where racism left off by substituting molecular differences for skin color differences will not be easy. Two actions, however, seem necessary. First, genetic privacy must be protected. No one's genes should be analyzed without express authorization, and, of course, no "genetic identity cards" should be permitted. Second, pseudoscientific projects that purport to identify genetic differences between "races" should be rejected.

The Prospect of Genetic Genocide

Screening genomes to detect differences creates more opportunities for discrimination. Using the new genetics to try to make a "better human" by genetic engineering goes beyond

discrimination to elimination by raising the prospect of genetic genocide. Is this inflammatory language justified?

The project of genetic engineering will begin with the genetic replication of humans by somatic cell nuclear transfer, known simply as cloning. Cloning to create a child who is a genetic replica of an existing human makes a mockery of human dignity both by undermining the individuality and liberty of the clone child, and by turning the child into a product of our own will and technique. The immediate danger, of course, is that as products, the human rights of the clone children will be suspect, and as copies of originals they will inevitably be treated (and treat themselves) as second class citizens.

Cloning, however, is only the beginning of the genetic engineering project. The next steps involve attempts to "cure" or "prevent" genetic diseases, and then to "improve" or "enhance" genetic characteristics to create the superhuman or posthuman.

It is this project that creates the prospect of genetic genocide as its most likely conclusion. This is because, given the history of humankind, it is extremely unlikely that we will see the posthumans as equal in rights and dignity to us, or that they will see us as equals. Instead, it is most likely either that we will see them as a threat to us, and thus seek to imprison or simply kill them before they kill us. Alternatively, the posthuman will come to see us (the garden variety human) as an inferior subspecies without human rights to be enslaved or slaughtered preemptively.

It is this potential for genocide based on genetic difference, that I have termed "genetic genocide," that makes species-altering genetic engineering a potential weapon of mass destruction, and makes the unaccountable genetic engineer a potential bioterrorist. This may seem overblown, but as a recent analysis of the failure of the United States to take action to prevent the genocide in Rwanda concludes, failure to act need not be based on failure to understand the facts: "Any failure to fully appreciate the genocide stemmed from political, moral, and imaginative weaknesses, not information ones."

The hopeful aspect of the new genetics is that it can lead us to see our species in new and deeper ways, and help us to form what Vaclav Havel has termed our "species consciousness." A species-level consciousness will help us to imagine the likely consequences of our genetic science and to take effective steps to try to prevent predictable disasters.

What Should be Done?

Bioethics has been called on to save us from the potential harms of the new genetics, but with its focus on individual decisions made in the context of the doctor-patient relationship, it cannot help us confront species-wide issues. Although bioethics can help, a much more potentially effective framework is the language and practice of international human rights. My own view is that the threat by cults and others operating on the margins of human society to clone a human being creates an opportunity for the world to act preventively in ways that have been either extremely difficult or impossible.

Specifically, I believe it is now reasonable and responsible to suggest that UNESCO's *Universal Declaration on the Human Genome and Human Rights*, and the overwhelming repulsion of peoples and governments around the world to the plan to clone humans, can be followed by a formal treaty on The Preservation of the Human Species. This treaty should

ban both species-altering techniques and species-endangering experiments. Specifically, techniques that propose to alter a fundamental beneficial characteristic of being human should be banned. (The alteration could be accomplished either by making the characteristic optional, such as by making sexual reproduction optional by adding cloning—asexual replication—to the ways humans could have children, or by altering the genetic code of an embryo in a way that the resulting child would be seen as a member of a human subspecies or of a new species.

Species-endangering experiments are those that would put the entire species at risk, such as current proposals to use pig organs for xenografts that risk the creation of a new lethal human virus that could be similar to HIV.

This treaty should also contain a democratic and accountable enforcement mechanism through a monitoring and review body. No experiments in the species-altering or species-endangering categories would be legal without this body's prior review and approval. By shifting the burden of proof to scientists and corporations to demonstrate that their interventions would more likely be beneficial than harmful to the species, the treaty would adopt the environmental movement's precautionary principle to species-altering and species-endangering interventions.

We have a tendency to simply let science take us wherever it will. But science has become so powerful, both in terms of making our lives better and raising the risk of species suicide, that we can no longer abdicate our mutual responsibility to each other as members of the human species.

Conclusion

In her disturbing and evocative novel of post-apartheid South Africa, The House Gun, Nadine Gordimer writes of Harold and Claudia Lindgard (the parents of a young man who has killed his friend):

> The Lindgards were not racist, if racist means having revulsion against skin of a different color, believing or wanting to believe that anyone who is not your own color or religion or nationality is intellectually and morally inferior. Claudia [a physician] surely had her proof that flesh, blood and suffering are the same, under the skin. Harold surely had his proof in his faith that all humans are God's creatures in Christ's image, none above the other. Yet neither had joined movements, protested, marched in open display, spoken out in defense of these convictions. They thought of themselves as simply not that kind of person; as if it were a matter of immutable determination, such as one's blood group, and not failed courage.

It took direct action to overcome apartheid. Although the Lindgards seemed to believe in behavioral genetic determinism, there is no gene (or blood characteristic) that codes for or excuses inaction in the face of actual or threatening human rights abuses. Inaction is the face of genism is not an option. We must work together to promote genetic privacy, prevent the cloning and genetic engineering of humans, and promote and protect universal human rights based on dignity and equality.

Without action on the species level genism will eclipse racism as the most destructive disease on the planet. We are all Africans. We are all humans.

IV

APPENDIX

The United Kingdom's Human Fertilization and Embryology Authority

The Human Fertilization and Embryology Authority (HFEA) was set up in the United Kingdom in 1991 following extensive national consultation and debate. It remains one of the few statutory bodies of its kind in the world, and is often pointed to as a model for regulating reproductive and genetic technologies.

The main functions of the HFEA are to:

- license and monitor all UK treatment clinics offering: in vitro fertilization (IVF), donor insemination (DI), storage of eggs, sperm or embryos.
- license and monitor all human embryo research.

In addition, the HFEA produces a Code of Practice which gives guidelines to clinics about the proper conduct of licensed activities, and keeps a formal register of information about donors, treatments and children born from those treatments.

The HFEA has 21 members, appointed by UK Health Ministers. The HFE Act requires that the Chairman, Deputy Chairman and at least half of the HFEA's membership are neither doctors nor scientists involved in human embryo research or providing infertility treatment.

Licensed clinics are inspected annually, by an inspection team consisting of a clinician, a scientist, a person with a background in another field, such as counseling, as well as a member of the HFEA's executive staff. The HFEA employs 65 part-time inspectors.

To grant a research license the HFEA must be satisfied that the use of human embryos is "necessary or desirable" for at least one of the following purposes:

- to promote advances in the treatment of infertility
- to increase knowledge about the causes of congenital disease
- to increase knowledge about the causes of miscarriages
- to develop more effective techniques of contraception
- to develop methods for detecting the presence of gene or chromosome abnormalities in embryos before implantation.

UK law does not permit certain activities involving human embryos. These include:

- keeping or using an embryo after the appearance of the primitive streak or after 14 days, whichever is the earlier
- placing a human embryo in an animal
- replacing a nucleus of a cell of an embryo with a nucleus taken from the cell of another person, another embryo, or subsequent development of an embryo

- altering the genetic structure of any cell while it forms part of an embryo
- using embryos for any other purposes except in pursuance of a license.

In 1998 the HFEA reiterated its opposition to human reproductive cloning, and forbade clinics to engage in activities specific to human cloning. The HFEA also called for national legislation to solidify the case against cloning.

Source: <www.doh.gov.uk/embryo.htm>

EXCERPTS FROM

INTERNATIONAL DECLARATIONS AND CONVENTIONS

UNESCO

UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS – 1996

ARTICLE 11

Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted.

ARTICLE 24

The International Bioethics Committee of UNESCO …. 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 identification of practices that could be contrary to human dignity, such as germ-line interventions.

Source: <www.unesco.org/human_rights/hrbc.htm>

COUNCIL OF EUROPE

CONVENTION ON HUMAN RIGHTS AND BIOMEDICINE – 1997

ARTICLE 13 – INTERVENTIONS ON THE HUMAN GENOME

An 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.

ARTICLE 14 – NON-SELECTION OF SEX

The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided.

Additional Protocol On The Prohibition Of Cloning Human Beings – 1998

ARTICLE 1

1) Any intervention seeking to create a human being genetically identical to another human being, whether living or dead, is prohibited.

2) For the purpose of this article, the term human being "genetically identical" to another human being means a human being sharing with another the same nuclear gene set.

Source: Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (ETS No. 164, 4/4/97; ETS No. 168, 12/1/98) <www.coe.fr/eng/legaltxt/164e.htm>

WORLD HEALTH ORGANIZATION

MEDICAL GENETICS AND BIOTECHNOLOGY: IMPLICATIONS FOR PUBLIC HEALTH – 2000

Genetic Interventions

17. Although genetic interventions hold great promise for the betterment of human health, vigilance should be exercised lest they contribute to racism, sexism, stigmatization, discrimination or the development of ruthless social policy. Eugenics and discriminatory policies based on genetic inheritance are unacceptable. Such policies violate human dignity and freedom and contravene the *Universal Declaration of Human Rights* and other international instruments, and should be condemned.

22. Gender is not a disease, and children must be recognized as human beings in their own right, and not the mere objects of their parents' wishes. Except for severe sex-linked genetic disorders, the use of genetic services for the purpose of gender-selection and consequent abortion is not acceptable.

23. Somatic gene therapy holds promise for improving human health, but possible risks for health must be balanced against possible benefits. In delivering such therapy, care must be exercised that vector/gene components do not contaminate germ lines. Germ-line therapy is not acceptable.

Cloning

26. As stated by resolutions WHA 51.10 and EB101.R25, "cloning for the replication of human individuals is ethically unacceptable and contrary to human dignity and integrity." Elaboration of the ethical, scientific, social and legal considerations that are the basis of this call for the prohibition of reproductive cloning should continue.

27. Deliberate reproductive cloning by embryo-splitting is also unacceptable. However, the use of embryo-splitting for non-reproductive purposes in the form of biopsies, for pre-implantation genetic diagnosis of serious clinical disorders, is seen as acceptable in some countries.

28. Major clinical therapeutic benefits may come from the development of cloning techniques for the production of human tissues and organs from non-embryonic cells. Relevant research should be undertaken provided that it does not involve reproductive cloning and that such applications are developed in conformity with ethical and legal requirements. Guidelines on the possible involvement of human gametes or embryos would need to be developed.

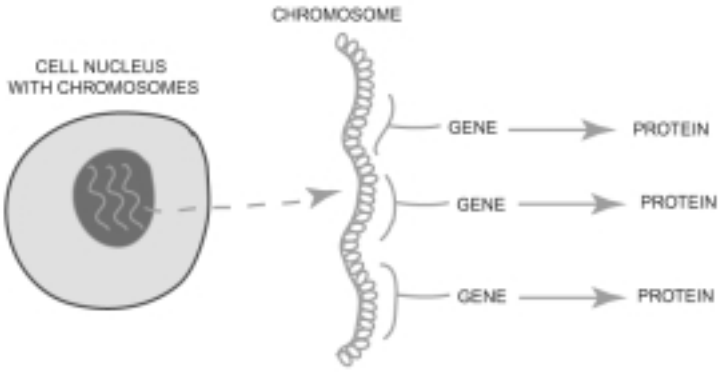
Source: Report of the informal consultation on Ethical Issues in Genetics, Cloning and Biotechnology: Possible Future Directions for WHO, Annex 1. Daar A, Mattei J-F. *Medical Genetics And Biotechnology: Implications For Public Health*, document WHO/EIP/GPE/00.1.

HUMAN CLONING AND INHERITABLE GENETIC MODIFICATION

The Basic Science You Need to Know

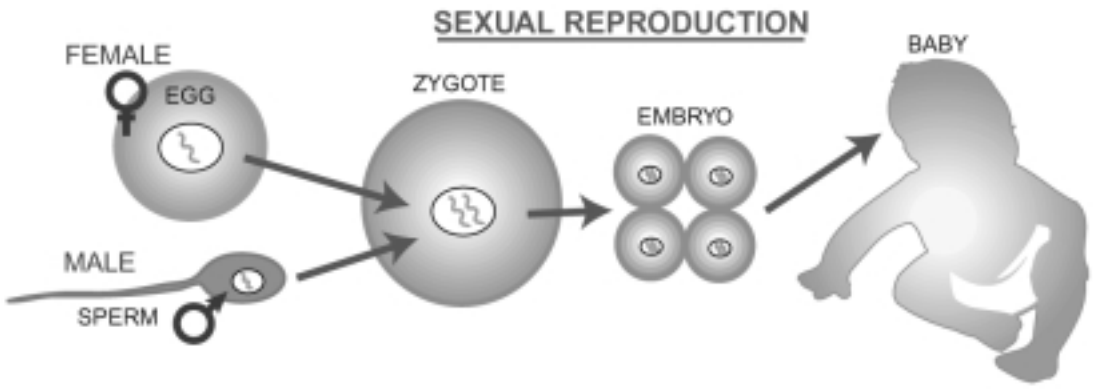
I. GENES

Genes are strings of chemicals that help create the proteins that make up your body. Genes are found in long coiled chains called chromosomes. They are located in the nuclei of the cells in your body:

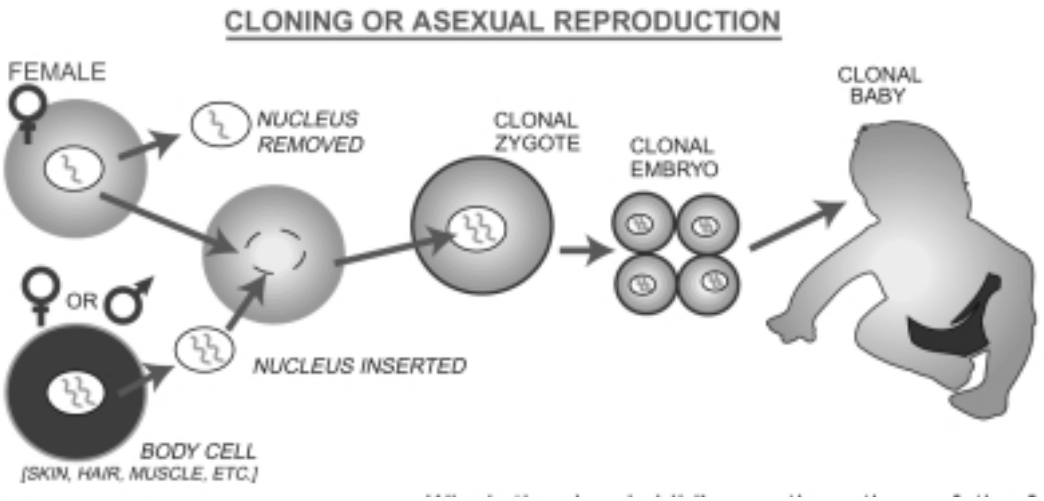


II. "THREE WAYS TO MAKE AN EMBRYO"

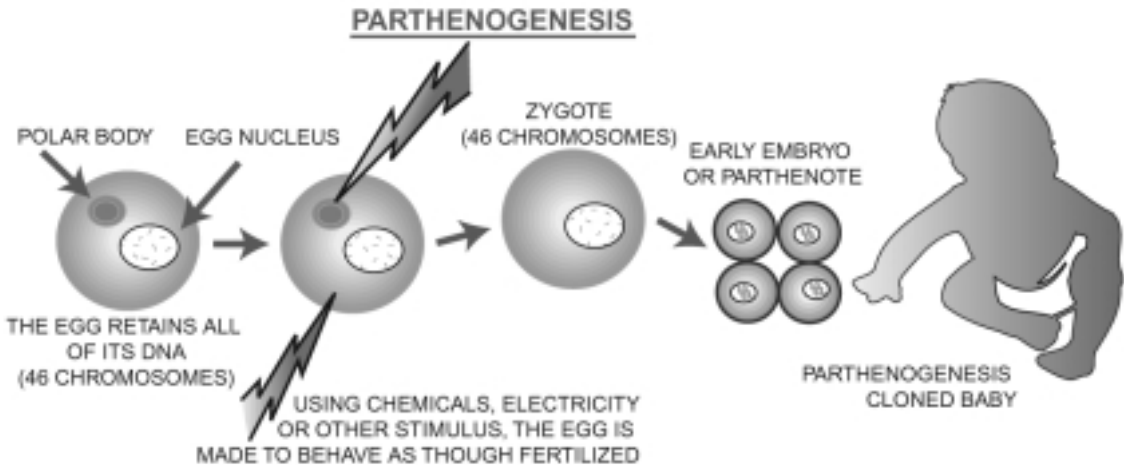
In sexual reproduction a child gets half its genes from its mother (in her egg) and half from its father (in his sperm):



Cloning is an asexual form of reproduction. All the child's genes would come from a body cell of a single individual:



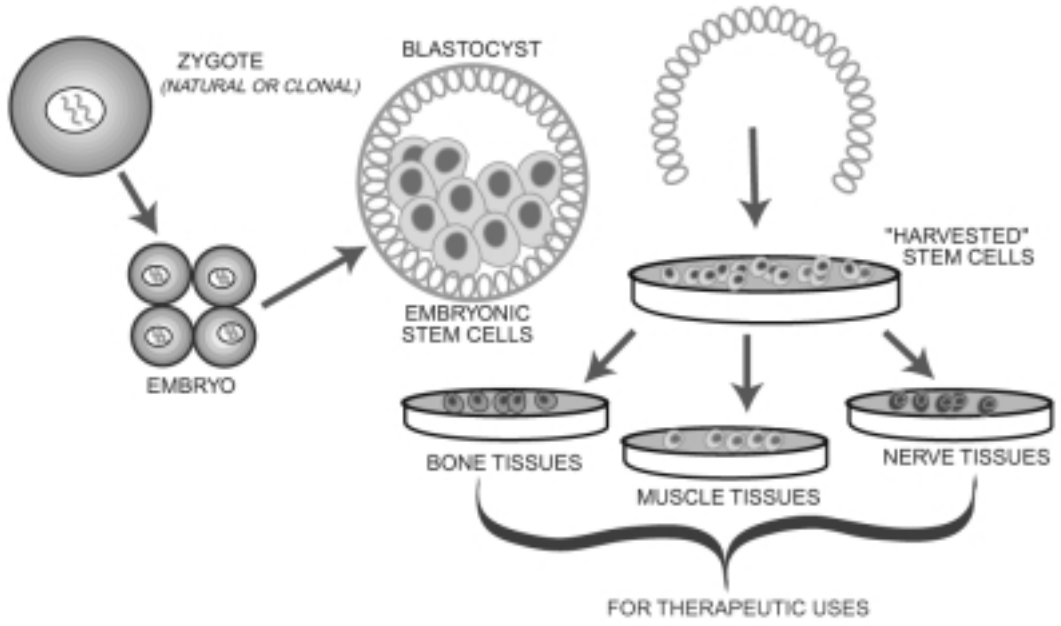
Parthenogenesis is similar to cloning. It creates a child from an unfertilized egg:



Who is the clonal child's genetic mother or father? As we understand those terms, a clonal child wouldn't have a genetic mother or father, it would have a single 'nuclear donor.' If a man cloned himself, would the child be that man's son or his twin brother? It would be neither, it would be a new category of biological relationship: his clone.

III. STEM CELLS

Stem cells are primordial cells capable of developing into a variety of types of cells. Some stem cells are found in the adult body. Others are found in very early embryos. These stem cells can be cultured in petri dishes and potentially used to generate "therapeutic tissues" or "spare organs":



Many people support the use of stem cells of both types for such therapeutic purposes. Many others support the use of adult stem cells for this purpose but oppose the use of embryonic stem cells, because they oppose the destruction or manipulation of human embryos.

IV. HUMAN CLONING: A CRITICAL DISTINCTION BETWEEN TWO APPLICATIONS

1. *Reproductive cloning* uses the cloning procedure to produce a clonal embryo which is implanted in a woman's womb with intent to create a fully formed living child – a clone – as shown in the diagram on page 48.
2. *Research cloning* – sometimes prematurely called therapeutic cloning – uses the cloning procedure to produce a clonal embryo, but instead of being implanted in a womb and brought to term it is used to generate stem cells, as shown in the diagram above, or for other research purposes.

The intent of using clonal embryos to generate stem cells is to investigate their possible use to create tissues for a clonal donor that would not be rejected by his or her immune system.

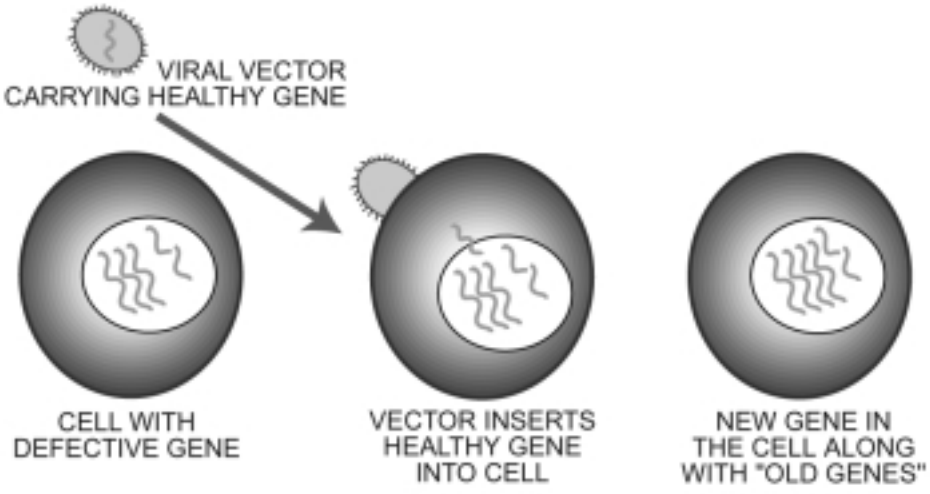
Most people oppose reproductive cloning. Some people oppose reproductive cloning but support research cloning. Others oppose research cloning as well as reproductive cloning, either because they are opposed to the destruction of embryos as a matter of principle, or because they feel the acceptance of research cloning will set us on a slippery slope to the acceptance of reproductive cloning and human germline manipulation.

It is possible to support embryonic stem cell research and still oppose research cloning.

v. HUMAN GENETIC MODIFICATION

Human genetic modification, or human genetic engineering, means changing the genes in a living human cell. Suppose you had a lung disease caused by defective genes in your lung cells. If there was a way to fix those genes, you might be cured.

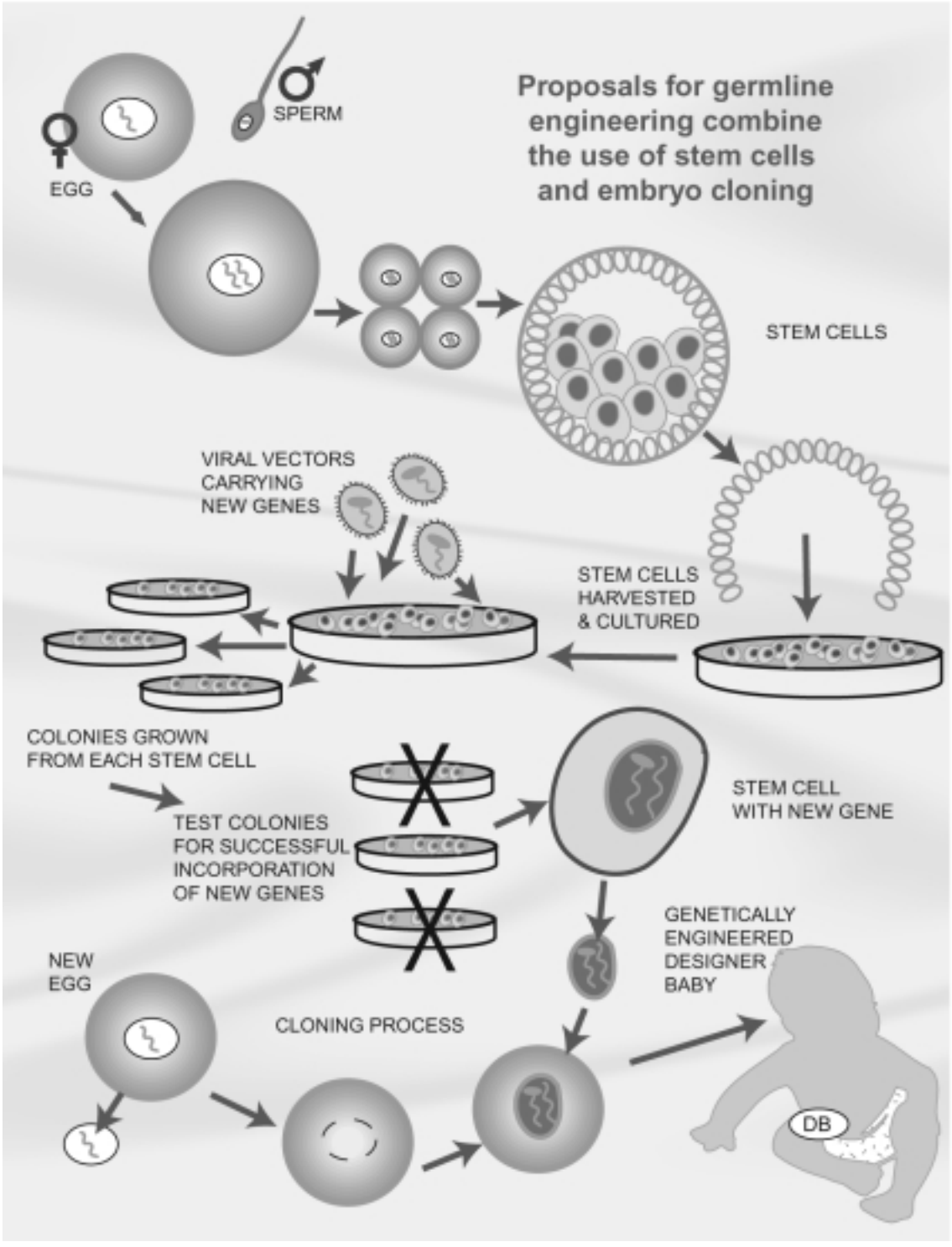
Scientists change the genes in living cells by putting the desired "new" gene into a virus-like organism which is allowed to get into your cells and which inserts the new gene into the cell along with the "old" genes:



vi. HUMAN GENETIC MODIFICATION: A CRITICAL DISTINCTION BETWEEN TWO APPLICATIONS

1. **"Somatic"** genetic modification is genetic modification that targets the genes in specific organs and tissues of the body of a single existing person without affecting genes in their eggs or sperm. Somatic gene transfer experiments are currently undergoing clinical trials, with mixed results to date. But they may someday be effective. The diagram above shows how somatic genetic modification works.

2 **"Inheritable"** or **"germline"** genetic modification is genetic modification that targets the genes in eggs, sperm, or very early embryos. The alterations affect every cell in the body of the resulting individual, and are passed on to all future generations. Inheritable genetic modification (IGM) is banned in many countries but not yet in the U.S. The diagram below shows how inheritable genetic modification might work.



VIII. PRE-IMPLANTATION GENETIC DIAGNOSIS AND SELECTION (PGD)

Many people assume that inheritable genetic modification is necessary to allow couples at risk of passing on a genetic disease to avoid doing so. This is not so. Procedures already exist that make this possible, including adoption and gamete and embryo donation. In addition the alternative of **pre-implantation diagnosis and selection** allows couples to have a child that is fully genetically related to both of them and which does not carry the genetic disease about which they are concerned.

The PGD procedure begins in the same way that germline engineering would, with an in-vitro fertilization (IVF) procedure, but instead of seeking to change the genes in unhealthy embryos it simply selects the healthy embryos themselves for implantation in the mother:

This technique is more straightforward than inheritable genetic modification, and does not open the door to an out-of-control techno-eugenic human future. Inheritable genetic modification would be required if a couple wished to endow their child with genes that neither member of the couple possesses. This is the "enhancement" scenario, which we believe would lead to a dystopic human future if it were allowed. PGD, on the other hand, would have a negligible effect on the human genome, even if it were widely used, because the procedure selects from the range of existing human traits, and would take many generations to have any widespread impact. But *engineering* the genes by means of inheritable genetic modification would allow novel forms of human life to be created within one generation.

While pre-implantation diagnosis and selection can be used for the acceptable reasons of preventing serious genetic disease such as Tay Sachs, it could also be used in ways that societies might find unacceptable, e.g., to select for cosmetic, behavioral, or other non-disease traits. Societies have the right and responsibility to decide which uses of such screening technologies should be allowed and which should be banned.

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Benign and Beneficent Applications of the New Human Genetic and Reproductive Technologies

The fact that human cloning and inheritable genetic modification need to be banned should not discourage the development of the many benign, beneficent and otherwise socially and ethically acceptable applications of genetic and reproductive technology. These more generally acceptable applications include:

1. MORE EFFECTIVE PHARMACEUTICALS AND MEDICAL TREATMENTS

Research using new genetic technologies is already helping to increase our understanding of human biology and to uncover the mechanisms of disease. We may find that many diseases have forms that use different molecular mechanisms. Different forms of asthma, for example, would be treated with different drugs. Such research may lead to the identification of new targets for pharmaceutical intervention and the accurate designing of drugs to those targets, which in theory could lead to fewer side effects.

2. NEW DIAGNOSTICS

A major promise of human genetics research is the discovery of genetic variations that underlie differences in the efficacy of drugs, and the occurrence of side effects, in different people. It should then be possible to restrict the use of drugs to those people for whom they would be most effective and safe. Since many people die from drug side effects and trial-and-error prescription is dangerous, expensive, and wasteful, this could be a major benefit.

Prenatal and preimplantation screening can allow couples at risk of passing on serious gene-related diseases the ability to avoid doing so. These procedures should be subject to regulatory oversight to prevent abuses.

Research to identify genes which predispose us to common illnesses such as heart disease and diabetes may allow the development of tests that predict our likelihood of getting such diseases. This might allow people to change their lifestyles to reduce their risk of developing disease. Caution and regulatory oversight will be necessary, however, to prevent misuses of such techniques.

3. SOMATIC GENE THERAPY

Attempts at somatic gene therapy have had few successes thus far but it may eventually become an effective treatment for at least some medical conditions. Combined with stem cell techniques and possibly tissue engineering, it is possible that many degenerative diseases could be treated. However, somatic gene transfer techniques might also be used for "enhancement" purposes. Some of these applications might be inconsequential but others could be unacceptable.

4. TREATMENTS FOR INFERTILITY

The use of new reproductive technologies may help us better understand the causes of infertility and help many infertile women and men to have children. However, these technologies can be abused in ways that either cause immediate harm or open the door to eugenic applications. They should be strictly regulated. At a minimum, fertility clinics and other sites using human gametes and embryos should be licensed by a public authority with the power to suspend the license for violations of laws and regulations.

5. IDENTIFICATION

"Genetic fingerprints" are already in use by police forces and have proved effective in both securing convictions and establishing innocence. Genetic testing may also be used for establishing paternity. Such uses of DNA for identification should not be used in ways that compromise civil liberties.