Should We Genetically Modify our Children?

Capps Center for the Study of Ethics, Religion, and Public Life at UCSB
March 3, 2016

Marcy Darnovsky, PhD
Center for Genetics and Society
Mission: For responsible uses and effective social governance of human genetic and assisted reproductive technologies

Values

- social justice
- human rights
- the public interest
CGS Selected to Host a Public Fellow by the American Council of Learned Societies

Applications for CGS Project Director on Race, Genetics, and Society can be made through the ACLS Public Fellows Program.

Talking Biopolitics with Paul Knoepfler and Nathaniel Comfort


Extreme Genetic Engineering and the Human Future
Reclaiming Emerging Biotechnologies for the Common Good

The Center for Genetics and Society and Friends of the Earth examine the human applications of synthetic biology. This 50-page report challenges claims that this new set of genetic engineering techniques should be seen as “the future of manufacturing, engineering and medicine.”
“The not-too-distant future"
Reproductive cloning
“Seizing control of human evolution”

Scientists say that, with gene therapy, they may soon be able to cure a child’s inherited disease before he is even born. But should they be allowed to create kids with made-to-order traits? BY SHARON BEGLEY

It is only a matter of time, one day—a day probably no more distant than the first wedding anniversary of a couple who are now teenage sweethearts—a man and a woman will walk into an in vitro fertilization clinic and make scientific history. Their problem won’t be infertility, the reason couples now choose IVF. Rather, they will be desperate for a very special child, a child who will yoke a family curse. To create their dream child, doctors will fertilize a few of the woman’s eggs with her husband’s sperm, as IVF doves do today. But then they will inject an artificial human chromosome, carrying made-to-order genes like pearls on a string, into the fertilized egg. One of the genes will carry instructions ordering cells to commit suicide gradually. Then the doctors will place the embryo into the woman’s uterus. If her baby is a boy, when he becomes an old man he, like his father and grandfather before him, will develop prostate cancer. But the cell-suicide genes will make his prostate cells self-destruct. The man, unlike his ancestors, will not die of the cancer. If his sperm, his sons will beat prostate cancer, too.

Genetic engineers are preparing to cross what has long been an ethical Rubicon. Since 1990, gene therapy has meant sifting a healthy gene into the cells of one of a patient suffering from a genetic disease. Soon, it may mean something much more momentous: altering a fertilized egg so that genes in all of a person’s cells, including eggs or sperm, also carry a gene that scientists, not parents, have implanted. When the pioneers of gene therapy first requested government approval for their experiments in 1997, they vowed they would never alter patients’ eggs or sperm. That was then. This is now. One of these pioneers, Dr. W. French Anderson of the University of Southern California, recently put the National Institutes of Health on notice. Within two or three years, he said, he would ask approval to use gene therapy on a fetus that has been diagnosed with a deadly inherited disease. The therapy would cure the fetus before it is born. But the introduced genes, though targeted at only blood or immune-system cells, might inadvertently slip into the child’s egg or sperm cells, too. If that happens, the genetic change would affect that child’s children and grandchildren.

"Life would enter a new phase," says biophysicist Gregory Stark of UCLA, "one in which we seize control of our own evolution." And since the gene that the doctors gave him escaped into every cell of his body, including his sperm, his sons will beat prostate cancer, too.

What we worry? DNA tricks may ease ethical concerns about "playing God!"
Designer Babies

Neil just a few years ago, making a baby boy or a baby girl was pretty much a hit-or-miss affair. Not anymore. Parents who have access to the latest genetic testing techniques can now predetermine their baby's sex with great accuracy—just like Monique and Scott Collins learned to their delight two years ago, when their long-wanted daughter Jessica was born after genetic prescreening at a fertility clinic in Fairfax, Va.

And baby Jessica is just the beginning. Within a decade or two, it may be possible to screen kids almost before conception for an enormous range of what body type they'll have, their hair and eye color, what sorts of diseases they will be naturally resistant to, and even, conceivably, their IQ and personality type.

In fact, if genetic therapy lives up to its promise, parents may one day be able to go beyond simply tailoring traits and start actually inserting the genes they want—perhaps even genes that have been crossed in a lab. Before the new millennium is many years old, parents may be getting to totally change and pick from a list of options the very traits that define their child. This may mean having a child who learns to walk before they can crawl, or one who is a voracious reader in tenth grade.

The prospect of designer babies, like many of the ethical controversies posed to the genetic revolution, is continuing to broaden the world as rapidly that doctors, ethicists, religious leaders and politicians are just starting to grasp the implications—and trying to decide how they feel about it all.

What people think

Role of a total disease

Tests greater intelligence

Influence boost on weight

Differences

Should parents who genetically linked diseases be required to test their children for these?

Yes &

No &
“GenRich” and “Naturals”

Eventually the GenRich class and the Natural class will become...entirely separate species with no ability to cross-breed.
Goal: To make inheritable genetic modification “acceptable” to the public.

Conclusion: “The question is not if, but when and how.”
“We have created a society that is so technologically complex that we must now create people who are smart enough to manage it.”

Daniel Koshland
"If you could find the gene which determines sexuality and a woman decides she doesn't want a homosexual child, well, let her."

"People say it would be terrible if we made all girls pretty. I think it would be great."
“We’re not your real parents - actually you’re a genetically modified tomato”

Reproduced by kind permission of PRIVATE EYE magazine/Simon Meyrick Jones
Convention on Biomedicine and Human Rights

Biomedicine and human rights
The Oviedo Convention and its additional protocols
“If we cross that fateful threshold, I don't see how we can ever return.”
Public interest organizations
Gene editing
Using CRISPR

**The tools**
- Guide RNA
- Cas9 cutting protein
- Replacement DNA sequence

**STEP 1**
Guide RNA finds target DNA in cell

**STEP 2**
Cas9 protein cuts DNA strands

**STEP 3**
Replacement DNA inserted

Source: The Economist
CRISPR developers
Scientists are developing ways to edit the DNA of tomorrow’s children. Should they stop before it’s too late?
“Don’t edit the human germ line”

*Nature*

“Serious risks… the therapeutic benefits are tenuous…

a path towards… genetic enhancement.”
“A prudent path forward for genomic engineering and germline gene modification”

*Science*
Gene-edited human embryos

“CRISPR/Cas9-mediated gene editing in human tripornuclear zygotes”

Protein & Cell
Biologists Call for Halt to Gene Editing Technique in Human

“The technique could be used to cure genetic diseases, but also to enhance qualities like beauty or intelligence. The latter is a path that many ethicists believe should never be taken.”
Reactions in the US
National Academies

International Summit on Human Gene Editing
A Global Discussion

CHINESE ACADEMY OF SCIENCES
THE ROYAL SOCIETY
U.S. NATIONAL ACADEMY OF SCIENCES
U.S. NATIONAL ACADEMY OF MEDICINE
“Editing Humanity”
1 Risky human experimentation

- Off-target and inaccurate “edits”
- Unpredictable effects
- Irreversible alterations
2 Thin medical justification

- Other options in almost all cases
  - PGD
  - Prenatal screening
  - Adoption
  - Third-party gametes
3 Humans as engineered products

- Experimentation on another’s body
- Pre-determined biological mold
- Foreclosing an “open future”
4 The common heritage of humanity

- Our shared humanity is the basis of human rights and social equality
- Targeting disfavored traits
Prohibited by law in more than 40 countries
Prohibited by binding Council of Europe treaty
UNESCO declaration
Discouraged by NIH & FDA, but no US law
Public polling shows strong opposition
A backlash against use of gene editing to treat diseases in existing people?
New “bad” & “good” genes, reflecting existing prejudices

Intensification of global disparities

Introduction of new kinds of inequality and discrimination
“Brave New Genome”

“Would the “best” genomes go to the most privileged?

Eric Lander
“The primary moral goal for today’s bioethics can be summarized in a single sentence.

“Get out of the way.”
Gene editing could correct genetic mutations for serious illnesses. Will it also create a new eugenics of personal choice?

Nathaniel Comfort