Human Gene Editing for Reproduction: What’s at Stake? Where Should We Draw the Lines?

BioLaw and Health Policy Society
Center for Law and the Biosciences

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Marcy Darnovsky, Center for Genetics and Society
Biopolitics

Biotech & Big Pharma | “Cheap White Eggs” | Clinical Trials | Cloning
| CRISPR | Disability Rights | DNA Forensics | Egg Retrieval

Embryo Selection | Environmentalism | Eugenics | Forced Sterilization | Gamete Donors | “Gay Gene” | Genetic Discrimination
| Human Germline Gene Editing

Human Rights | Inheritable Genetic Modification | LGBTQI
| Direct-to-Consumer Genetics | Prenatal Screening | “Precision Medicine” | PGD | Public Interest | Race | Religion

Reproductive Justice

Sequencing & Genomics | Sex Selection | Stem Cell Research | Social Justice
| Surrogacy | Synthetic Biology | Transhumanism | "Warrior Gene“ | Viking Sperm
Earlier this month
Today’s talk

- Key distinctions in the debate about human germline modification
- Summary of argument against
- Some 20th-century history: US eugenics
- Some turn-of-the century history: An early chapter in the debate
- The current conversation
Somatic vs germline

- “Somatic genetic modification”
  - Affects tissues and cells in existing patients
  - Not inheritable

- “Germline genetic modification”
  - Changes genes in eggs, sperm, embryos
  - Inheritable and irreversible
Therapy vs. enhancement

- A clear distinction? Or inherently blurry and subjective?
- A feasible distinction in policy or legal terms? Or impossible to implement or enforce?
Not safe

Profound risks to future children & generations...
Safer ways to have health children...
New forms of inequality?
20th-century eugenics

They came to have their babies. They went home sterilized.

no más bebés
no more babies

Tuesday, October 27, 2015
Room 32-155
5:30 P.M.
Screening + Q&A with filmmaker Renee Tajima-Peña
Healthy seed & fitter families

- Only healthy seed must be sown!
- Check the seeds of hereditary disease and unfitness by eugenics
- Fitter Families for Georgia
Early 2000s: Human clones? GM babies?

**TIME**

**Designer Babies**

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 wasn’t infertility, the reason couples now choose IVF. Rather, they will be desperate for a very special child, a child who will start a family curse. To create their desired child, doctors will fertilize a few of the woman’s eggs with her husband’s sperm, as IVF clinics do today. But then they will inject an artificial human chromosome, carrying a gene to order genes like pearls on a string, into the fertilized egg. One of the genes will carry instructions ordering cells to commit suicide (graph). 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 will look like his father and grandfather before him, will develop prostate cancer. But the cell-suicide gene will make his prostate cells self-destruct. The man, unlike his ancestors, will not die of the cancer. And since the gene that the doctors gave him copied itself into every cell of his body, including his sperm, his sons will have prostate cancer, too.

Genetic engineers are preparing to clone what has long been an ethical taboo: Rodent. Since 1998, gene therapy has meant slipping a healthy gene into the cells of one organ of a patient suffering from a genetic disease. Soon, it may mean something even 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, bequeathed them. When the pioneers of gene therapy first requested government approval for their experiments in 1987, they vowed they would never alter patients’ eggs or sperm. That was then. This is now. One of those 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 the nth generation. "Life would enter a new phase," says bioethicist Gregory Stock of UCLA, "one in which we seize control of our own evolution."

Judging by the 70 pages of public comments NIH has received since Anderson submitted his proposal in September, the overwhelming majority of scientists and ethicists weighing in oppose gene therapy that changes the “germline” (eggs and sperm). But the opposition could be a

For couples who can’t have a child—or who have lost one—the unthinkable may soon be possible. Here are the perils.
“Eventually the GenRich class and the Natural class will become... entirely separate species with no ability to cross-breed.”

Lee Silver, Princeton biologist
“Engineering the Human Germline”

Goal: To make inheritable genetic modification “acceptable” to the public.

Conclusion: “The question is not if, but when and how.”
Fertility clinic of the future?

“You must act before you get pregnant. Don't be sorry after she's born. This really is a once-in-a-lifetime opportunity for your child-to-be.”
“The not-too-distant future”
Widespread international agreement
Convention on Biomedicine and Human Rights
Gene “editing”
“Engineering the Perfect Baby”

“Scientists are developing ways to edit the DNA of tomorrow’s children. Should they stop before it’s too late?”
“The return of eugenics”

“Researchers don’t like the word – but they're running ahead with the idea, and Britain is at the forefront.”
What the CRISPR experiments mean for humanity

“You can imagine ...rogue IVF clinics offering services guaranteeing offspring will have this or that trait.”
Genome editing: The age of the red pen

“It is now easy to edit the genomes of plants, animals and humans.”
“Don’t edit the human germ line”

*Nature*, March 2015

“Serious risks...the therapeutic benefits are tenuous...a path towards... genetic enhancement.”
“A prudent path forward for genomic engineering and germline gene modification”

Science, April 2015
Obama administration
CRISPR developers
National Academies
“You know I’m proud to have that German blood. There’s no question about it. Great stuff.”
Transhumanist Trump supporter

- Silicon Valley billionaire
- Transhumanism’s most generous supporter
- More than $4M for “work toward immortality”
On the other hand…

Rider in omnibus budget bill prohibits FDA from using funds to consider research that involves modifying human embryos
What next?

REPORT RELEASE PUBLIC BRIEFING

HUMAN GENOME EDITING: SCIENCE, ETHICS, AND GOVERNANCE

February 14, 2017
11:00 AM | Washington, DC
live webcast available

Register: nam.edu/HumanGeneEditing

#GeneEditStudy