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

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

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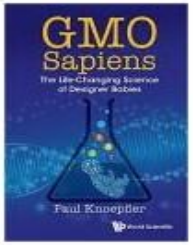
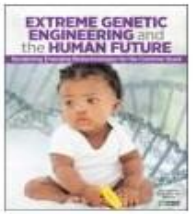
CGS Selected to Host a Public Fellow by the American Council of Learned Societies

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

Join us on January 26 for an online conversation about Paul Knoepfler's book, *GMO Sapiens: The Life-Changing Science of Designer Babies*.



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."

BIOPOLITICAL TIMES BLOG

- False inevitabilities and irrational exuberance
- Biopolitical News of 2015
- Top *Biopolitical Times* Posts of 2015
- Stem Cell Researcher to Reddit: "Ask Me Anything" on Human Genetic Modification

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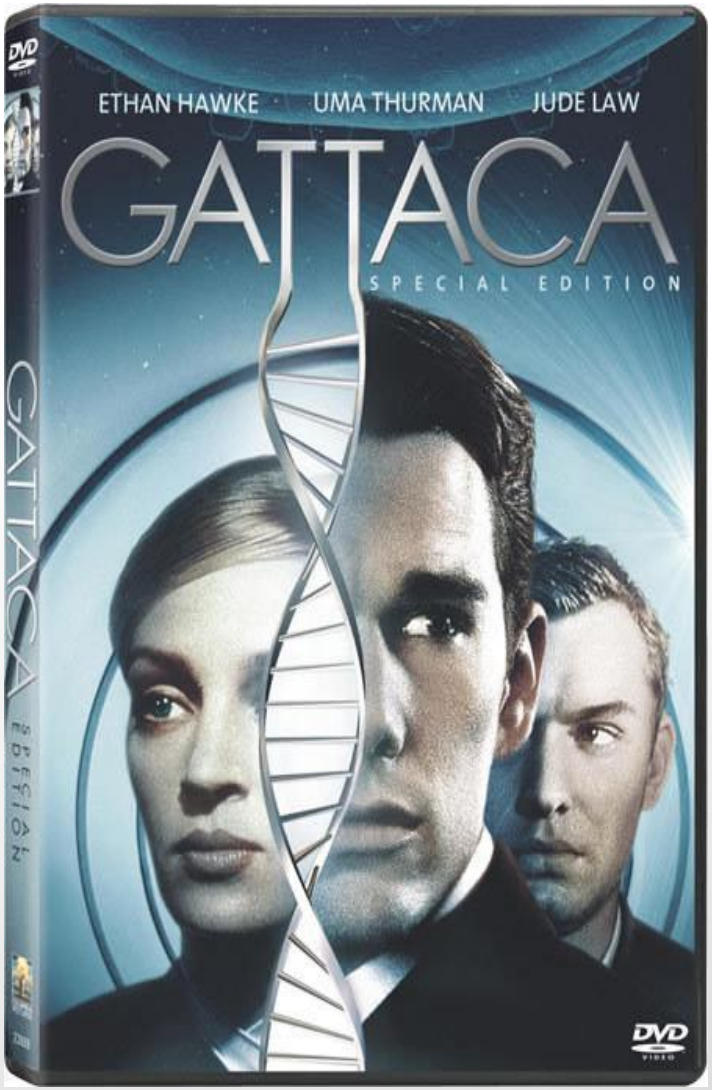
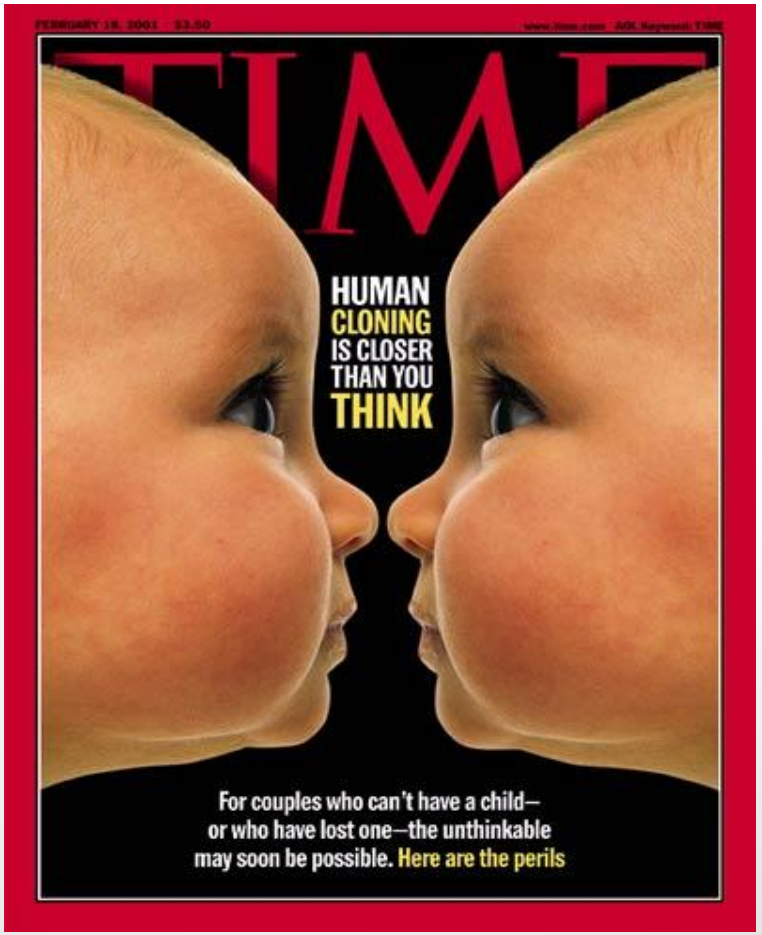
“The not-too-distant future"



Reproductive cloning



“Seizing control of human evolution”

This cover (and inside page, over) from *New Scientist* suggests both the profound consequentiality of the new human genetic technologies and their inherent potential brutality. It conveys as well the commitment that many scientists and science journalists share to the belief that the use of these technologies to create "superhumans" is all but inevitable.

SCIENCE

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 won't be infertility, the reason couples now choose IVF. Rather, they will be desperate for a very special child, a child who will elude 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 clinics 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 (graphic). 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 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 beat prostate cancer, too.

Genetic engineers are preparing to cross what has long been an ethical Rubicon. Since 1990, 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 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, 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 unto the nth generation. "Life would enter a new phase," says biophysicist 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

JON RILEY—STOCK SHOP

What, me worry? *DNA tricks may ease ethical concerns about 'playing God'*

“Designer Babies”

THE FUTURE OF MEDICINE

Parents can now pick a kid's sex and screen for genetic illness. Will they someday select for brains and beauty too?

Designer Babies

By MICHAEL D. LEMONICK

UNTIL 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—as Monique and Scott Collins learned to their delight two years ago, when their long-wished-for 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 attributes, such as how tall they're likely to be, what body type they will have, their hair and eye color, what sorts of illnesses they will be naturally resistant to, and even, conceivably, their IQ and personality type.

In fact, if gene therapy lives up to its promise, parents may someday be able to go beyond weeding out undesirable traits and start actually inserting the genes they want—perhaps even genes that have been crafted in a lab. Before the new millennium is many years old, parents may be going to fertility clinics and picking from a list of options the way car buyers order air conditioning and chrome-alloy wheels. "It's the ultimate shopping experience: designing your baby," says biotechnology critic Jeremy Rifkin, who is appalled by the prospect. "In a society used to cosmetic surgery and psychopharmacology, this is not a big step."

The prospect of designer babies, like many of the ethical conundrums posed by the genetic revolution, is confronting the world so rapidly that doctors, ethicists, religious leaders and politicians are just starting to grapple with the implications—and trying to decide how they feel about it all.

They still have a bit of time. Aside from gender, the only traits that can now be identified at the earliest stages of development are about a dozen of the most serious genetic diseases. Gene therapy in embryos is at least a few years away. And the gene or combination of genes responsible for most of our physical and mental attributes hasn't even been identified yet, making moot the idea of engineering genes in or out of a fetus. Besides, say clinicians, even if the techniques for making designer babies are perfected within the next decade, they should be applied in the service of disease prevention, not improving on nature.

But what doctors intend is not necessarily what's going to happen. Indeed, the technology that permitted the Collinses family to pick the sex of their child was first used to select for health, not gender per se. Adapting a technique used on livestock, researchers at the Genetics & IVF Institute in Fairfax took advantage of a simple rule of biology: girls have two X chromosomes, while boys have one X and one Y. The mother has only Xs to offer, so the balance of power lies with the father—specifically with his sperm, which brings either an X or a Y to the fertilization party.

As it happens, Y chromosomes have slightly less DNA than Xs. So by staining the sperm's DNA with a nontoxic light-sensitive dye, the Virginia scientists were able to sort sperm by gender—with a high rate of success—before using them in artificial insemination. The first couple to use the technique was looking to escape a deadly disease known as X-linked hydrocephalus, or water on the brain, which almost always affects boys.

But while the technique is ideal for weeding out this and other X-linked disorders, including hemophilia, Duchenne muscular dystrophy and Fragile X syndrome, most patients treated at Genetics & IVF want to even out their families—a life-style rather than a medical decision. The Fairfax clinic has been willing to help, but such a trend doesn't sit well with some other practitioners. "Our view at the moment," says Dr. Zev Rosenwaks, director of the Center for Reproductive Medicine and Infertility at Cornell Medical Center in New York City, "is that these techniques should be used for medical indications, not family balancing."

But now that parents know that the technology is available, and that at least some clinics will let them choose a child's gender for nonmedical reasons, it may be too late to go back. In a relatively short time, suggests Princeton University biologist Lee Silver, whose book *Remaking Eden* addresses precisely these sorts of issues, sex selection may cease to be much of an issue. His model is in vitro fertilization, the technique used to make "test-tube" babies. "When the world first learned about IVF two decades ago," he says, "it was horrifying to most people, and most said that they

WHAT PEOPLE THINK

If you could choose traits for your baby, would you choose to...

	Yes
Rule out a fatal disease	60%
Ensure greater intelligence	11%
Influence height or weight	12%
Determine sex	15%

Should parents with genetically linked diseases be required to test their children for them?

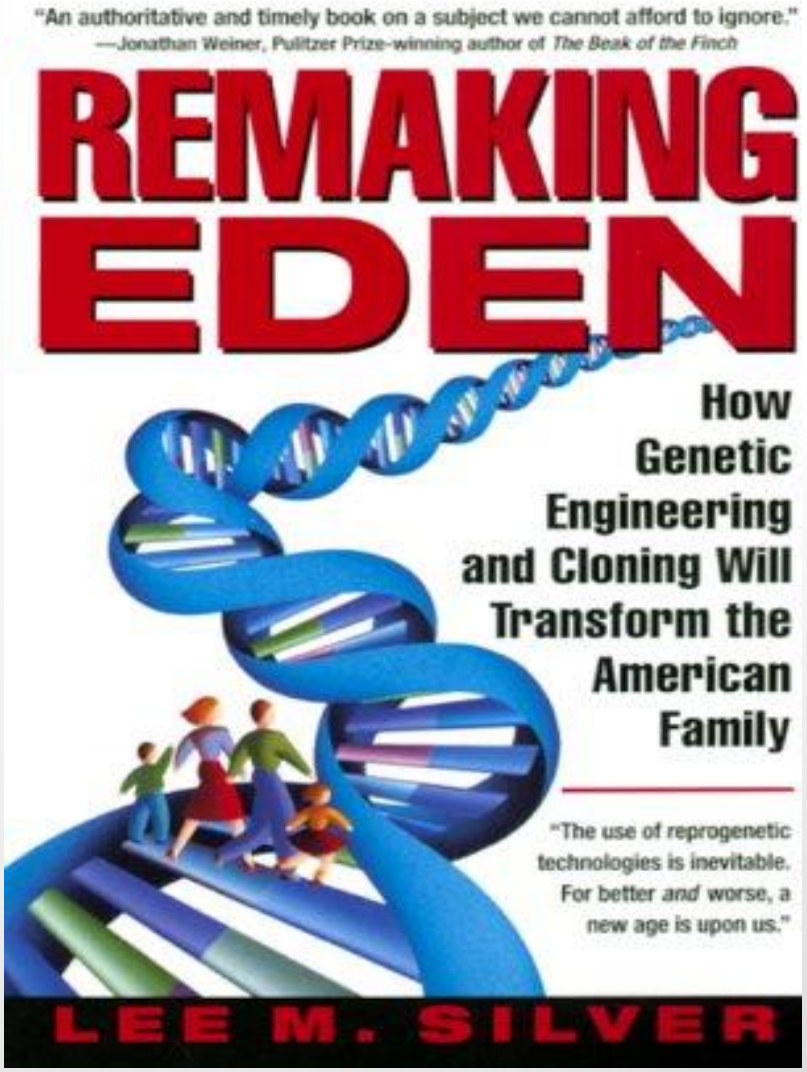
Yes 39% No 55%

TIME, JANUARY 11, 1999

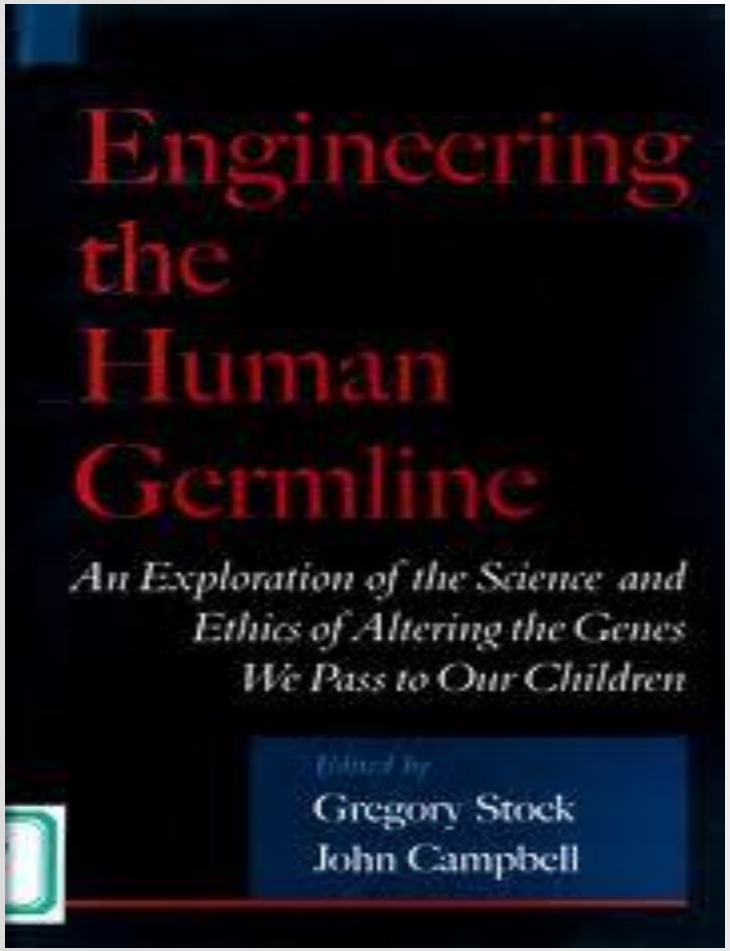
Illustrations for TIME by John Craig

“GenRich” and “Naturals”

Eventually the GenRich class and the Natural class will become…entirely separate species with no ability to cross-breed.



“Engineering the Human Germline”



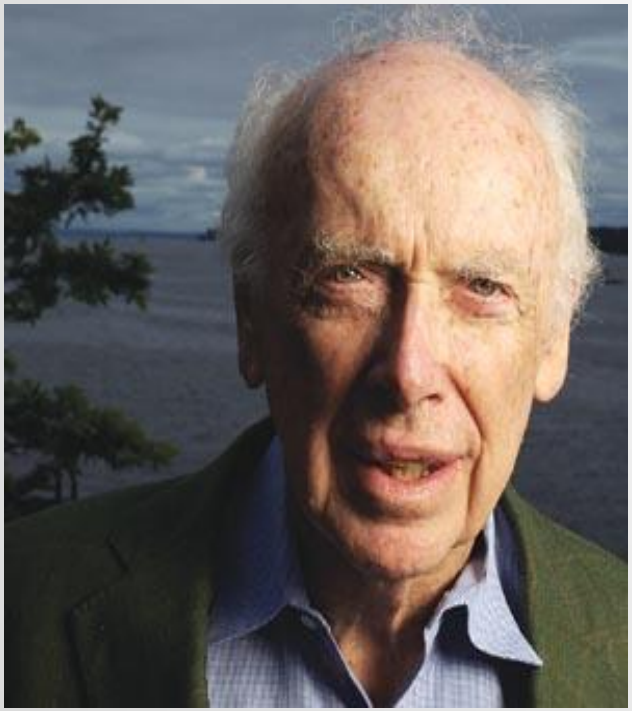
Goal: To make inheritable genetic modification “acceptable” to the public.

Conclusion: “The question is not if, but when and how.”

Daniel Koshland

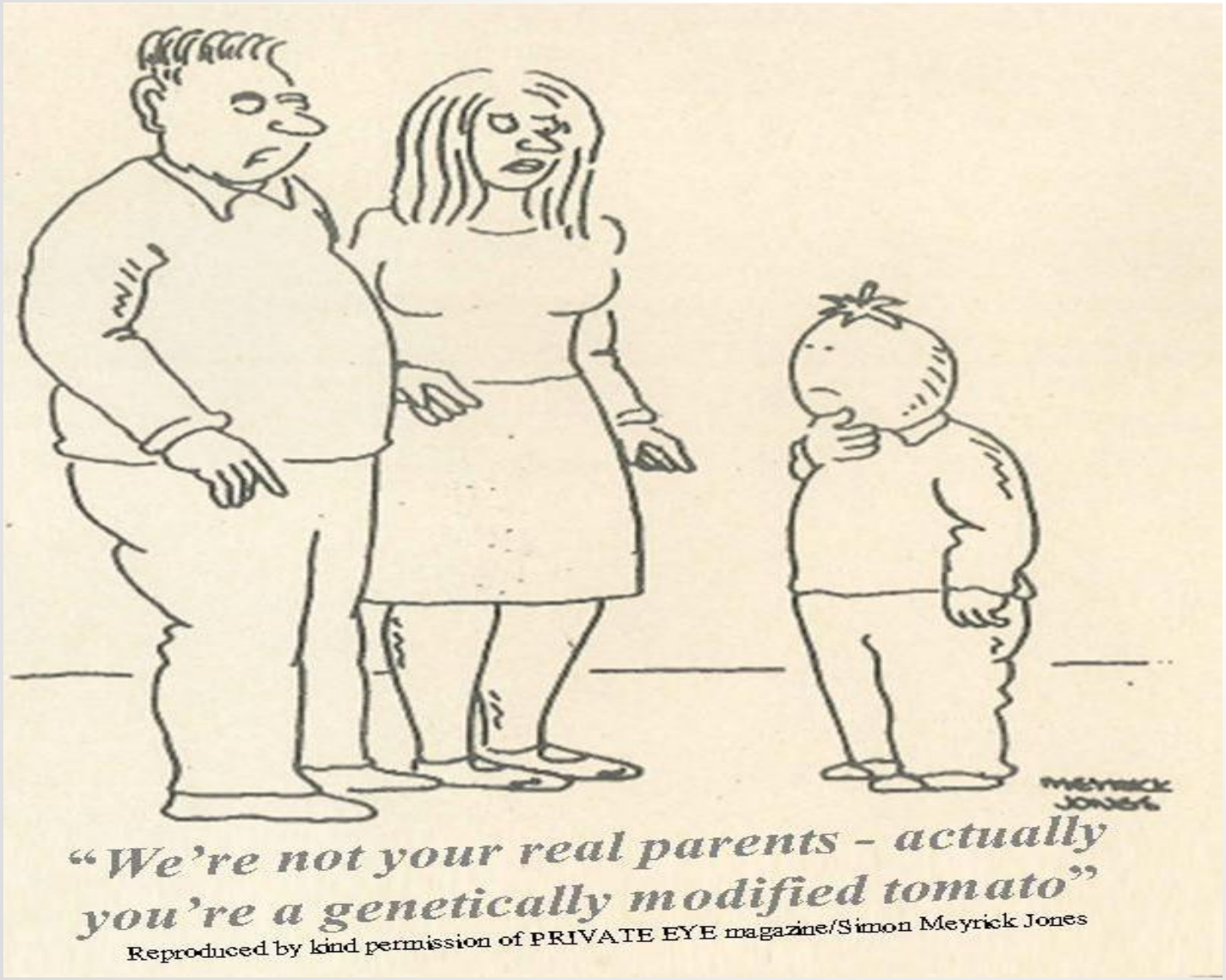
"We have created a society that is so technologically complex that we must now create people who are smart enough to manage it."

James Watson



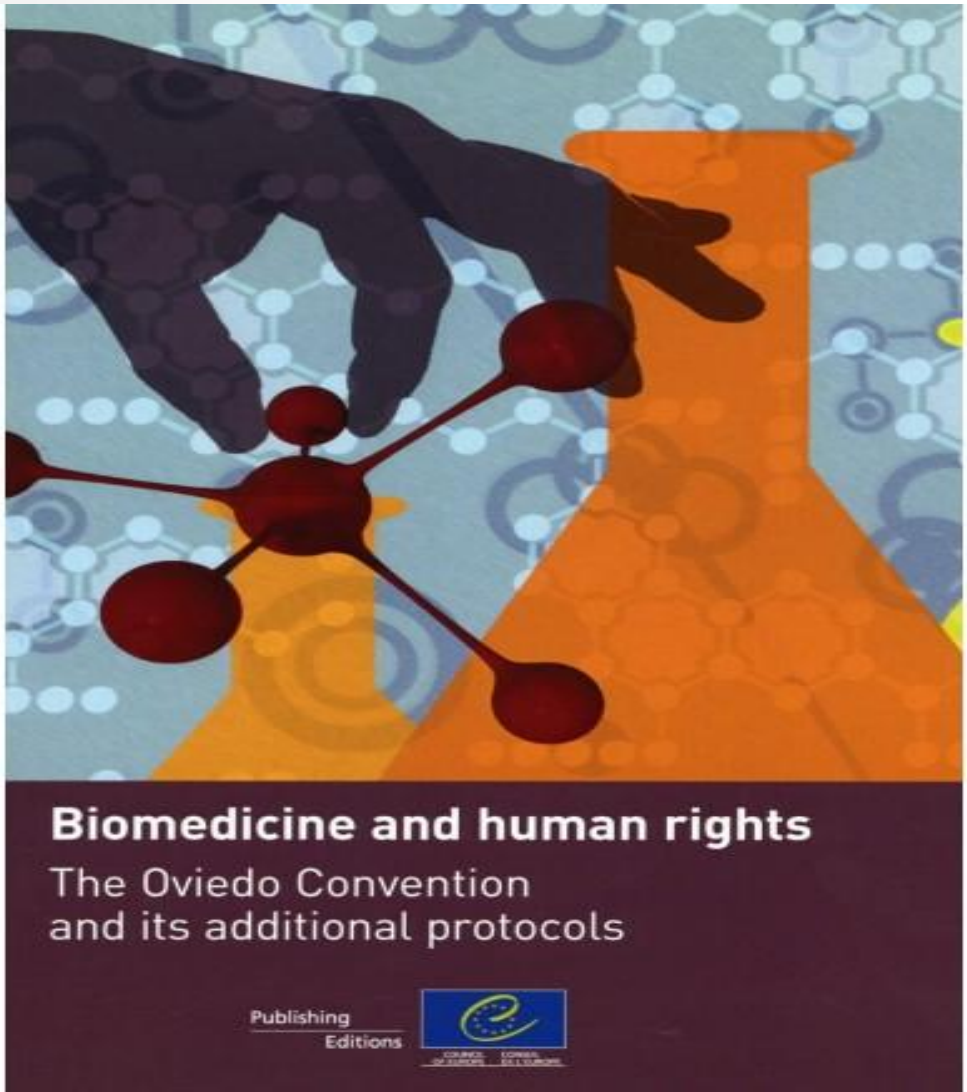
"If you could find the gene which determines sexuality and a woman decides she doesn't want a homosexual child, well, let her."

"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"

Convention on Biomedicine and Human Rights



Eric Lander

"If we cross that fateful threshold, I don't see how we can ever return."

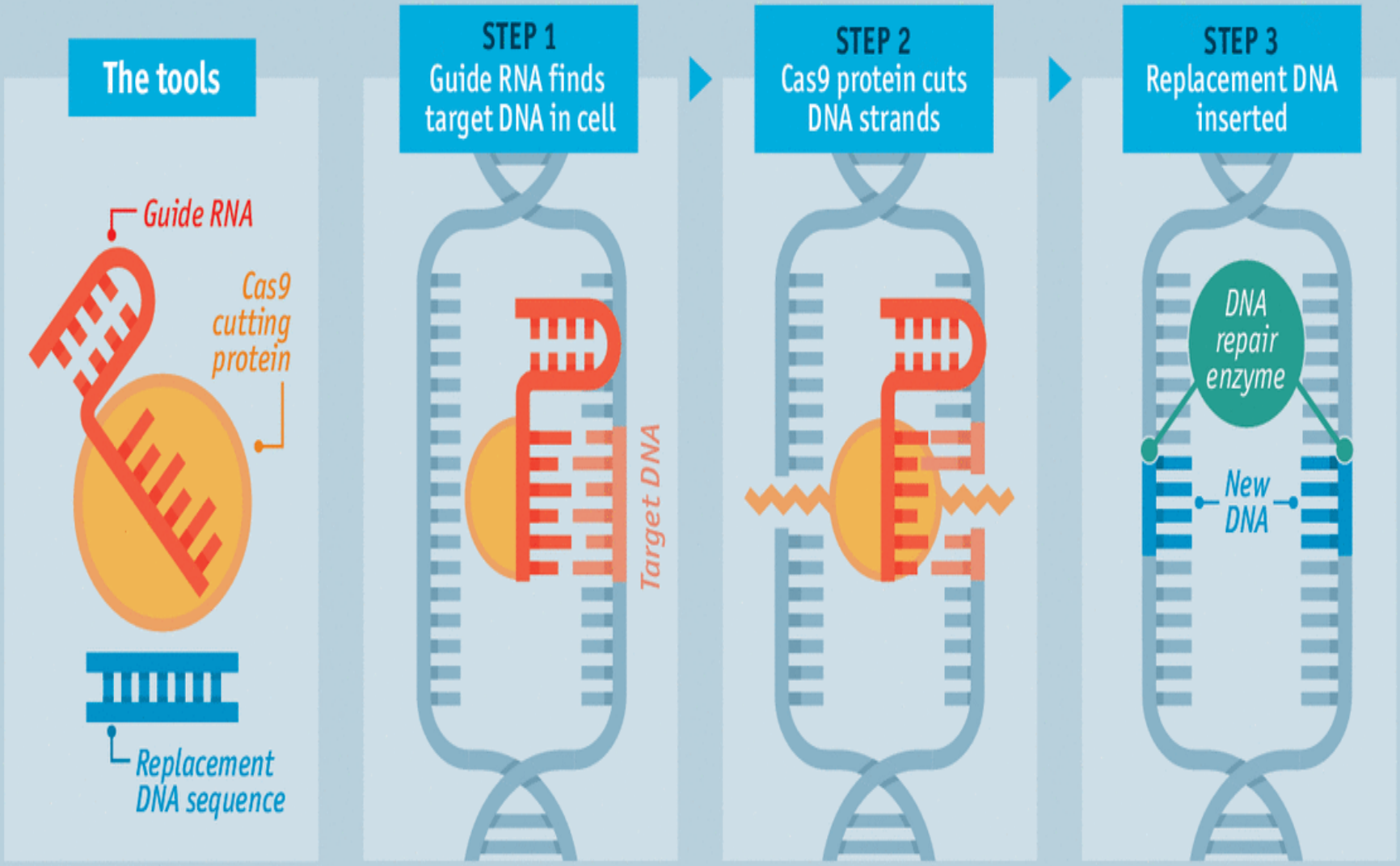
Public interest organizations

GeneWatch UK

CRG
Council for
Responsible
Genetics

Gene editing

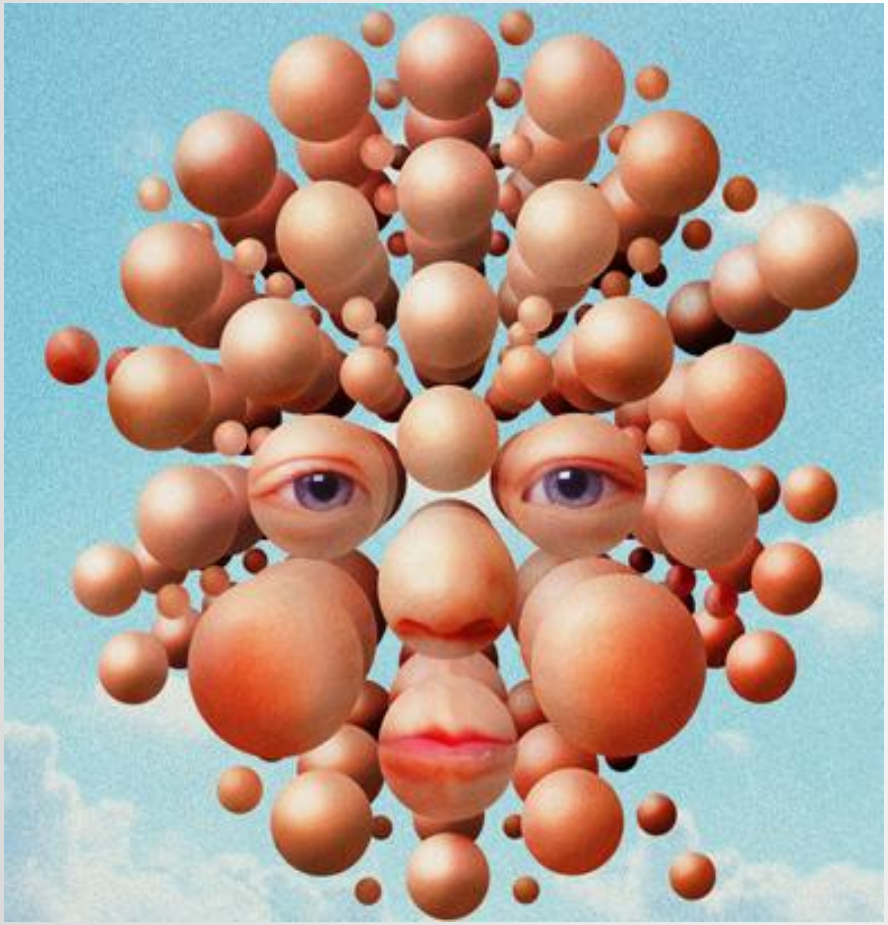
Using CRISPR



Source: *The Economist*

CRISPR developers

“Engineering the Perfect Baby”



MIT Technology Review

Scientists are developing ways to edit the DNA of tomorrow’s children.

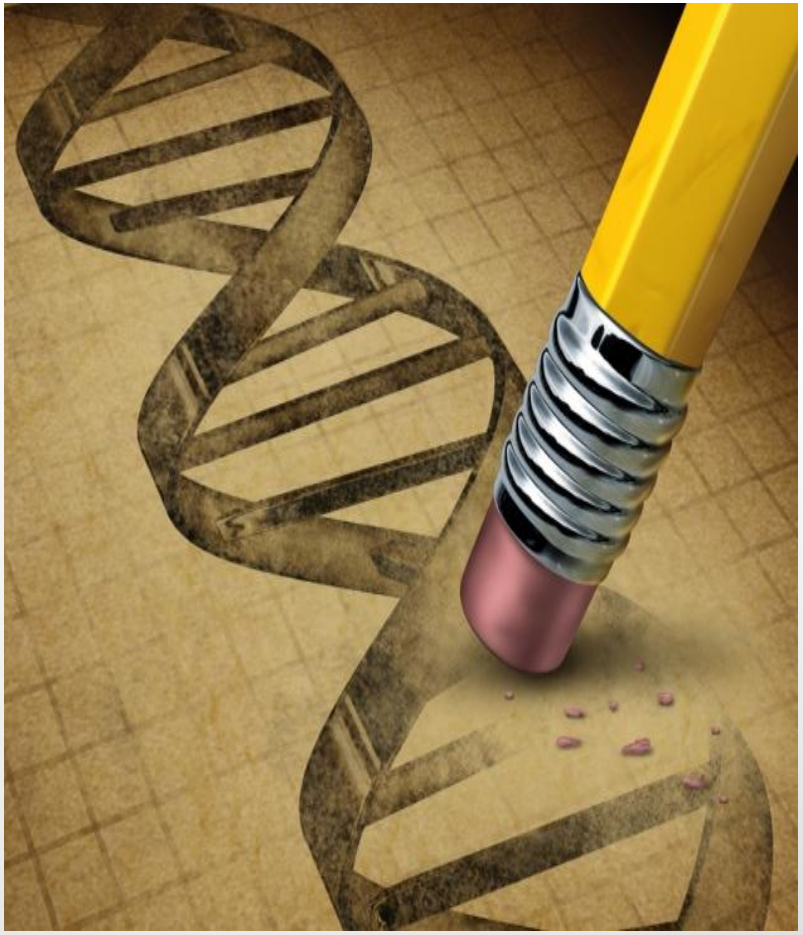
Should they stop before it’s too late?

“Don’t edit the human germ line”

Nature

“Serious risks…the therapeutic benefits are tenuous…

a path towards… genetic enhancement.”

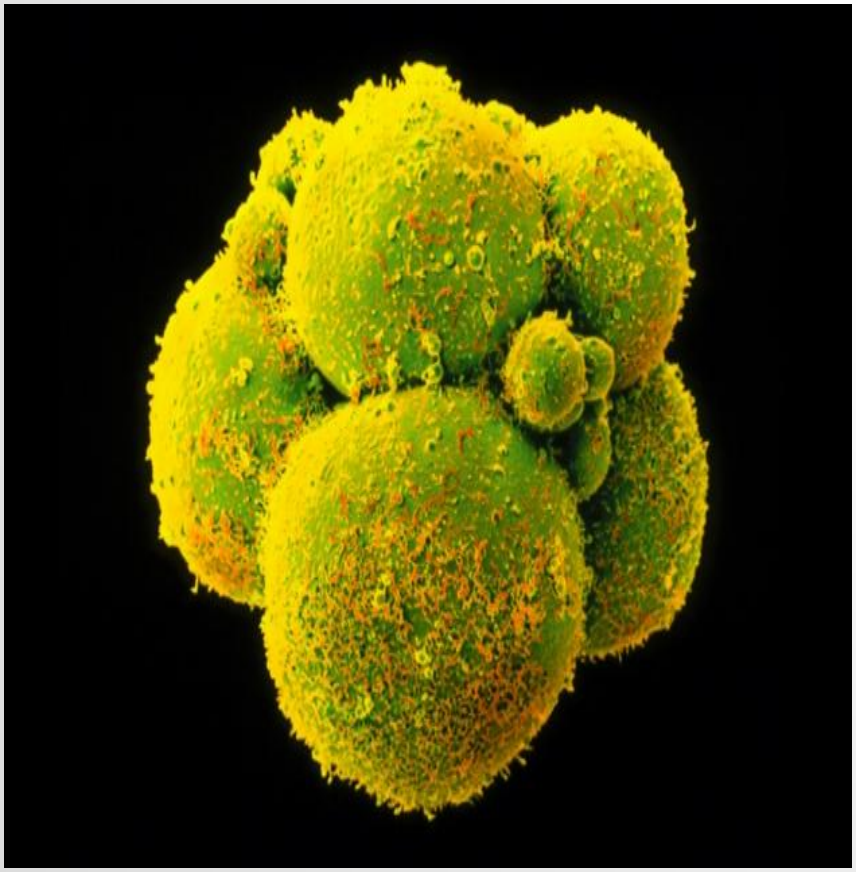


“A prudent path forward…”

Science

“A prudent path forward for genomic engineering and germline gene modification”

Gene-edited human embryos



"CRISPR/Cas9-mediated gene editing in human tripronuclear zygotes"

Protein & Cell

Front page of *The New York Times*

Biologists Call for Halt to Gene Editing Technique in Human

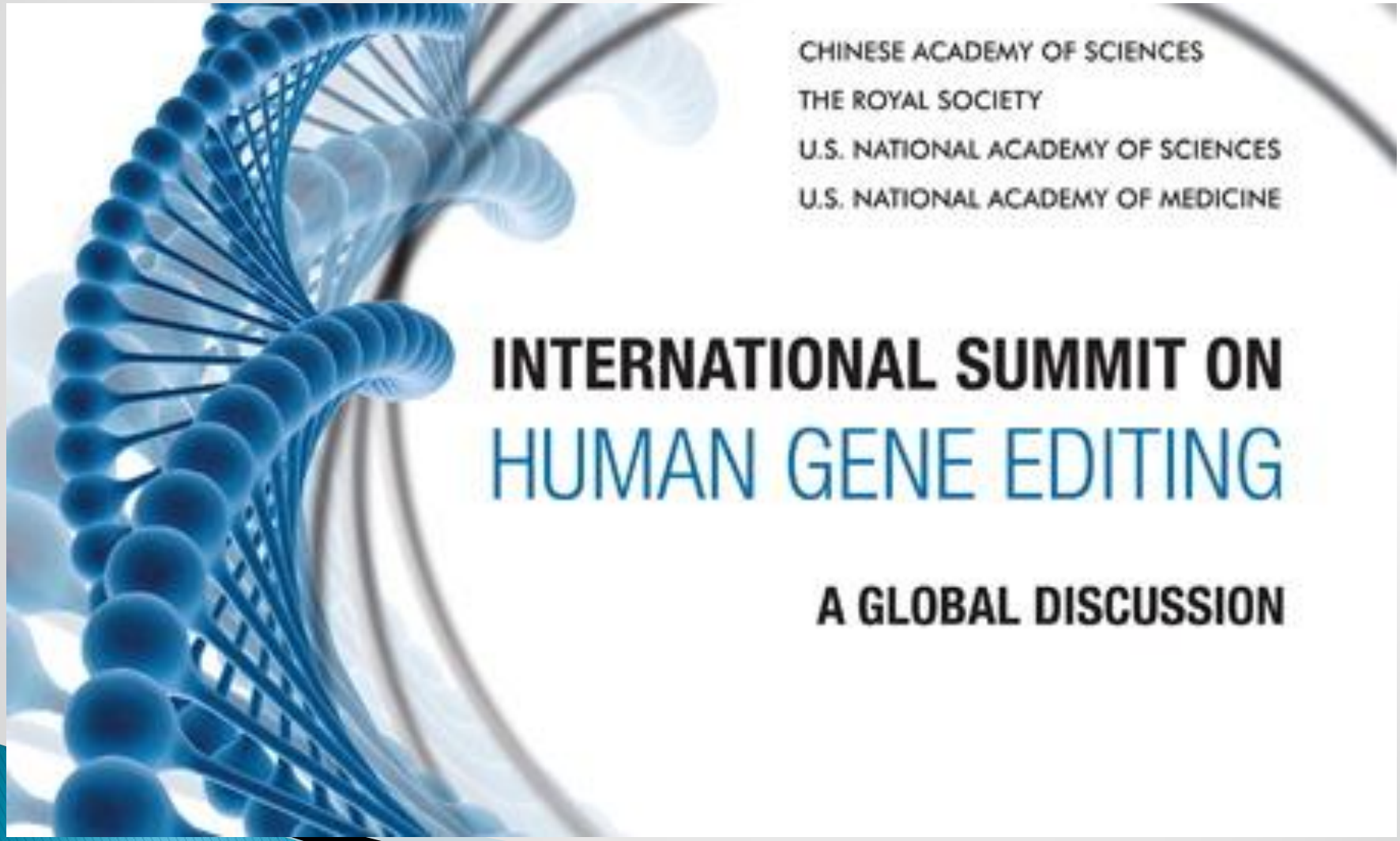
"The technique could be used to cure genetic diseases, but also to enhance qualities like beauty or intelligence. The latter is a path that many ethicists believe should never be taken."

Reactions in the US

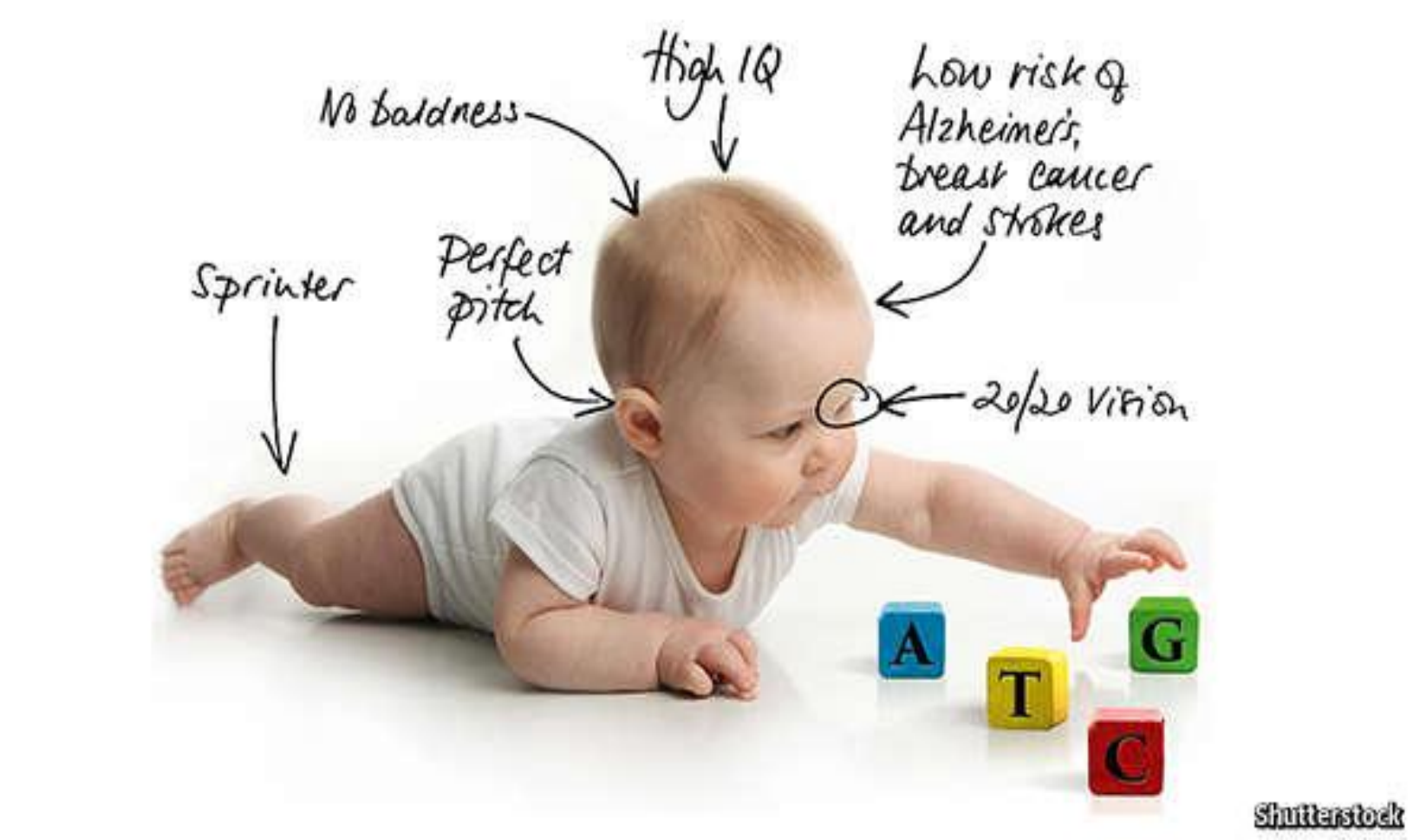
THE NATIONAL ACADEMIES

Advisers to the Nation on Science, Engineering, and Medicine

National Academies

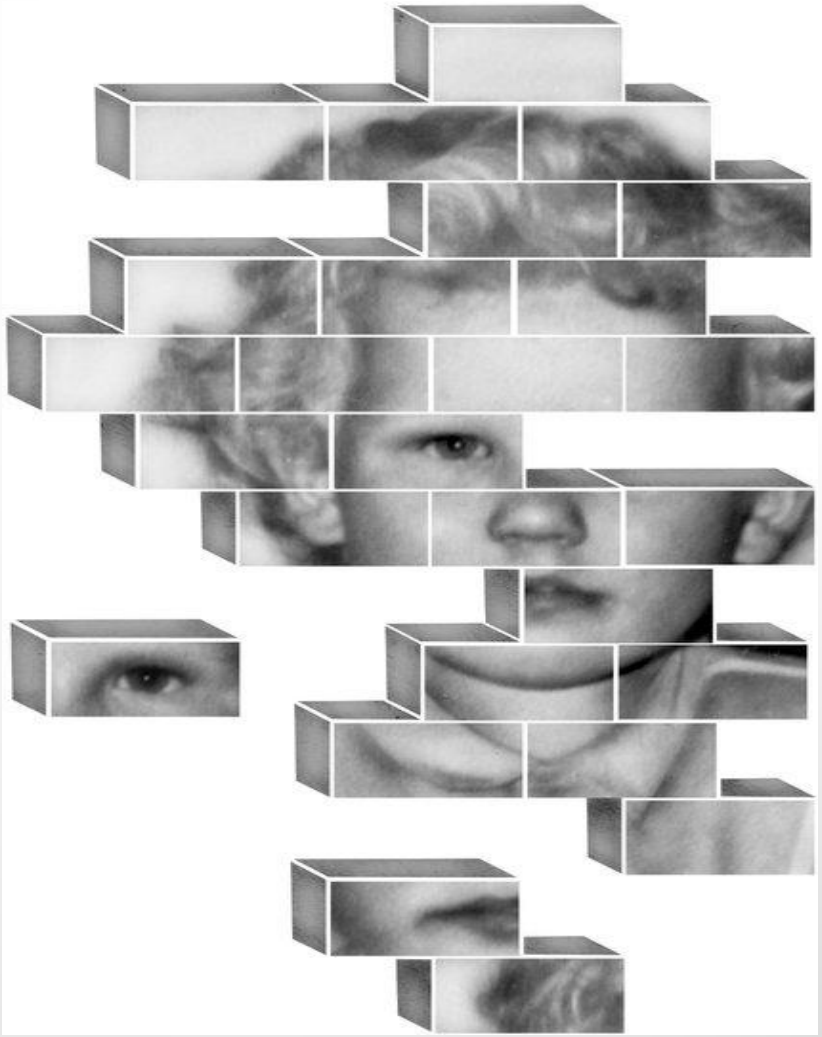


“Editing Humanity”



1 Risky human experimentation

- Off-target and inaccurate “edits”
- Unpredictable effects
- Irreversible alterations

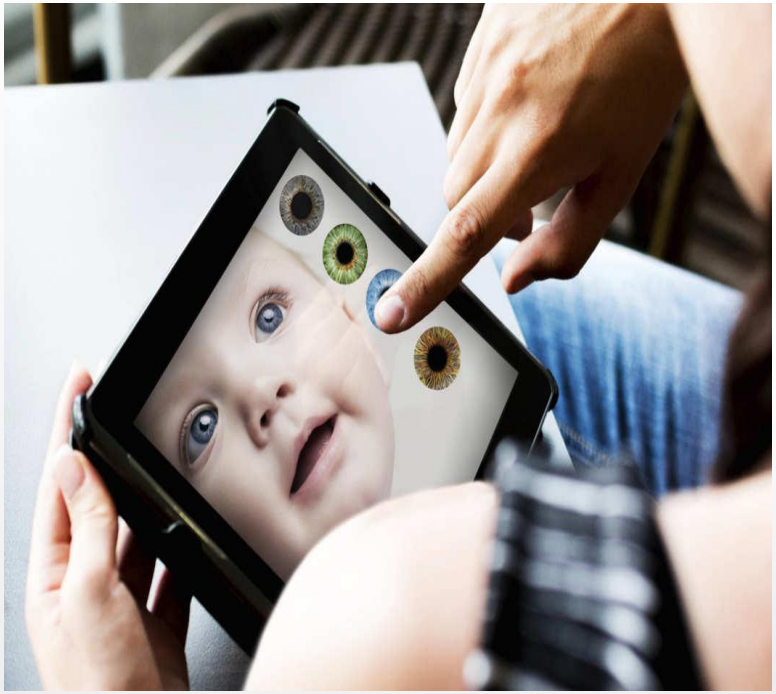


2 Thin medical justification

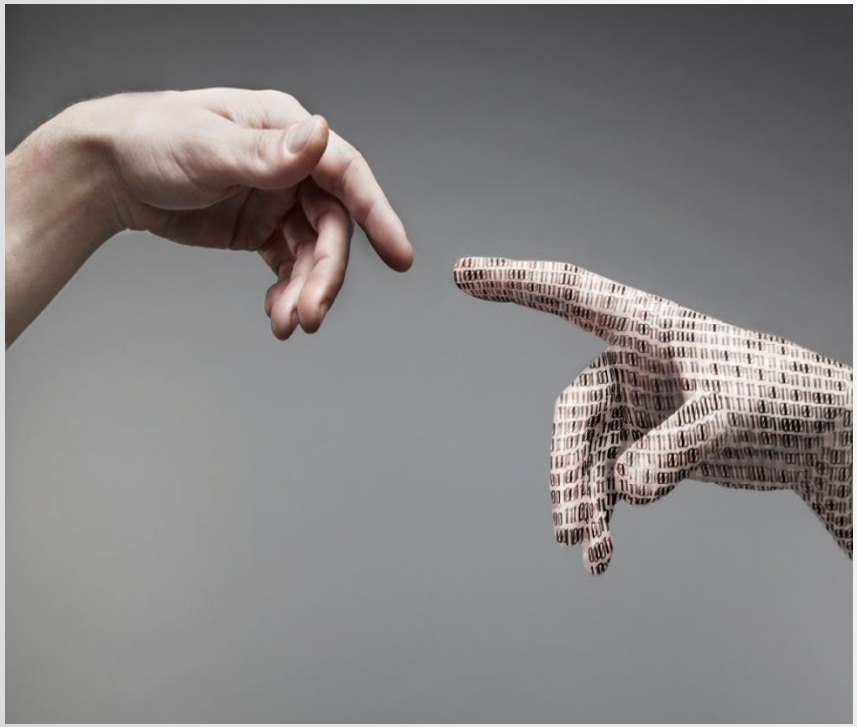
- Other options in almost all cases
  - PGD
  - Prenatal screening
  - Adoption
  - Third-party gametes

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

5 Undermining widespread policy agreements

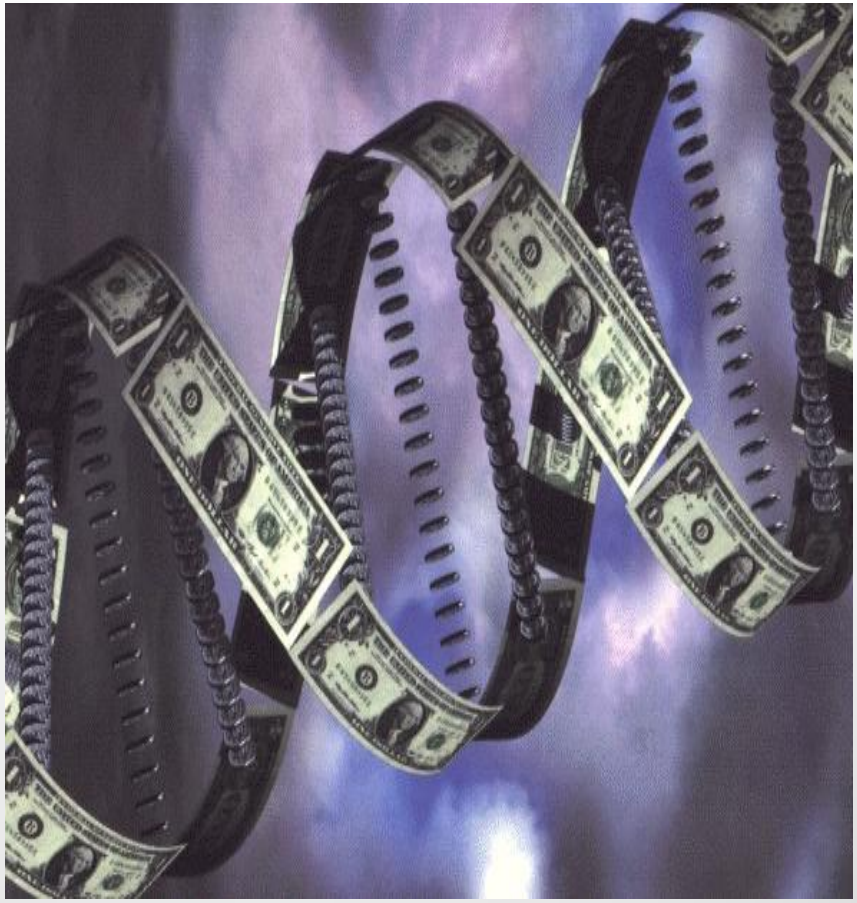
- Prohibited by law in more than 40 countries
- Prohibited by binding Council of Europe treaty
- UNESCO declaration
- Discouraged by NIH & FDA, but no US law

6 Eroding public trust in responsible science

- Public polling shows strong opposition
- A backlash against use of gene editing to treat diseases in existing people?

7 Reinforcing inequality, discrimination & conflict

- New “bad” & “good” genes, reflecting existing prejudices
- Intensification of global disparities
- Introduction of new kinds of inequality and discrimination



“Brave New Genome”

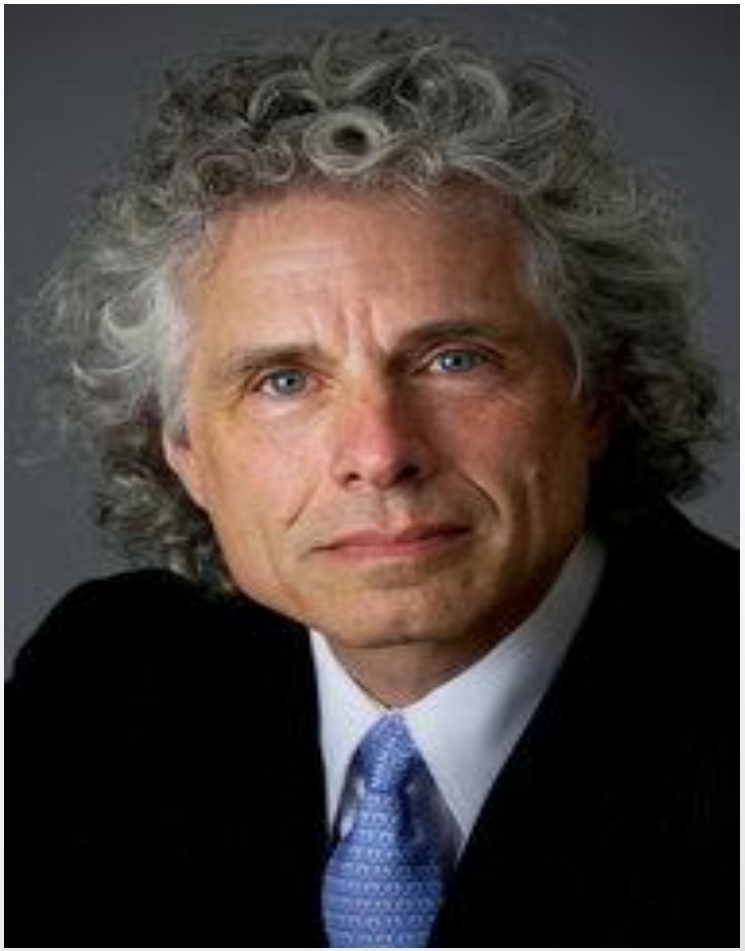
“Would the “best” genomes go to the most privileged?

Eric Lander

Steven Pinker

"The primary moral goal for today's bioethics can be summarized in a single sentence.

"Get out of the way."



”Can We Cure Genetic Diseases Without Slipping Into Eugenics?”

Gene editing could correct genetic mutations for serious illnesses. Will it also create a new eugenics of personal choice?

Nathaniel Comfort