Alliance for Disability Justice and Ethics in Reproductive Genetics

Stephanie Meredith, MA, DrPH

Katie Stoll, MS, CGC

Objectives

- Summarize the purpose of the Alliance for Disability Justice and Ethics in Reproductive Genetics
- Review the current landscape of reproductive genetics and causes for concern moving forward
- Compare proposed policy interventions aimed at addressing ethical challenges in prenatal technologies
- Brainstorm policy strategies

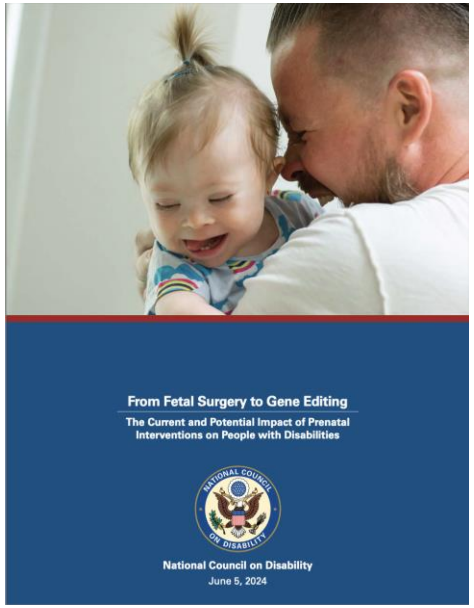
Stephanie Meredith, MA, DrPH : Disability and Health

Development Director, Lettercase Supervisor
Genetic Support Foundation

Author of NCD’s “From Fetal Surgery to Gene Editing: The Current and Potential Impact of Prenatal Interventions on People with Disabilities”

Mom of Andy, Kate, and Lily

Serves on Trisomy Collaborative Executive Committee with funding from New Venture Fund. No other conflicts of interest to declare.



From Fetal Surgery to Gene Editing

The Current and Potential Impact of Prenatal Interventions on People with Disabilities

National Council on Disability

June 5, 2024

Genetic Support Foundation

Katie Stoll, MS, CGC

Executive Director
Genetic Support Foundation

Serves on Trisomy Collaborative Steering Committee with funding from New Venture Fund

Genetic Support Foundation

Purpose of the Alliance

Update

- Update disability advocacy organizations about emerging ethical and disability justice issues in reproductive genetics.

Connect

- Connect disability advocacy organization leaders with leaders in the fields of bioethics, academics, health, and disability justice.

Identify and advance

- Collectively identify and advance 1–3 shared policy priorities each year that promote disability justice and ethical practices in reproductive genetics.

Collaborate on

- Collaborate on advocacy, public education, and policy efforts to amplify our collective voice.

1. Meet quarterly to review updates in the fields of genetics and disability
2. Identify collective policy priorities
3. Provide updates on individual and collective organizational strategies to address those policy priorities

Alliance Activities

Reproductive Genetic Technology

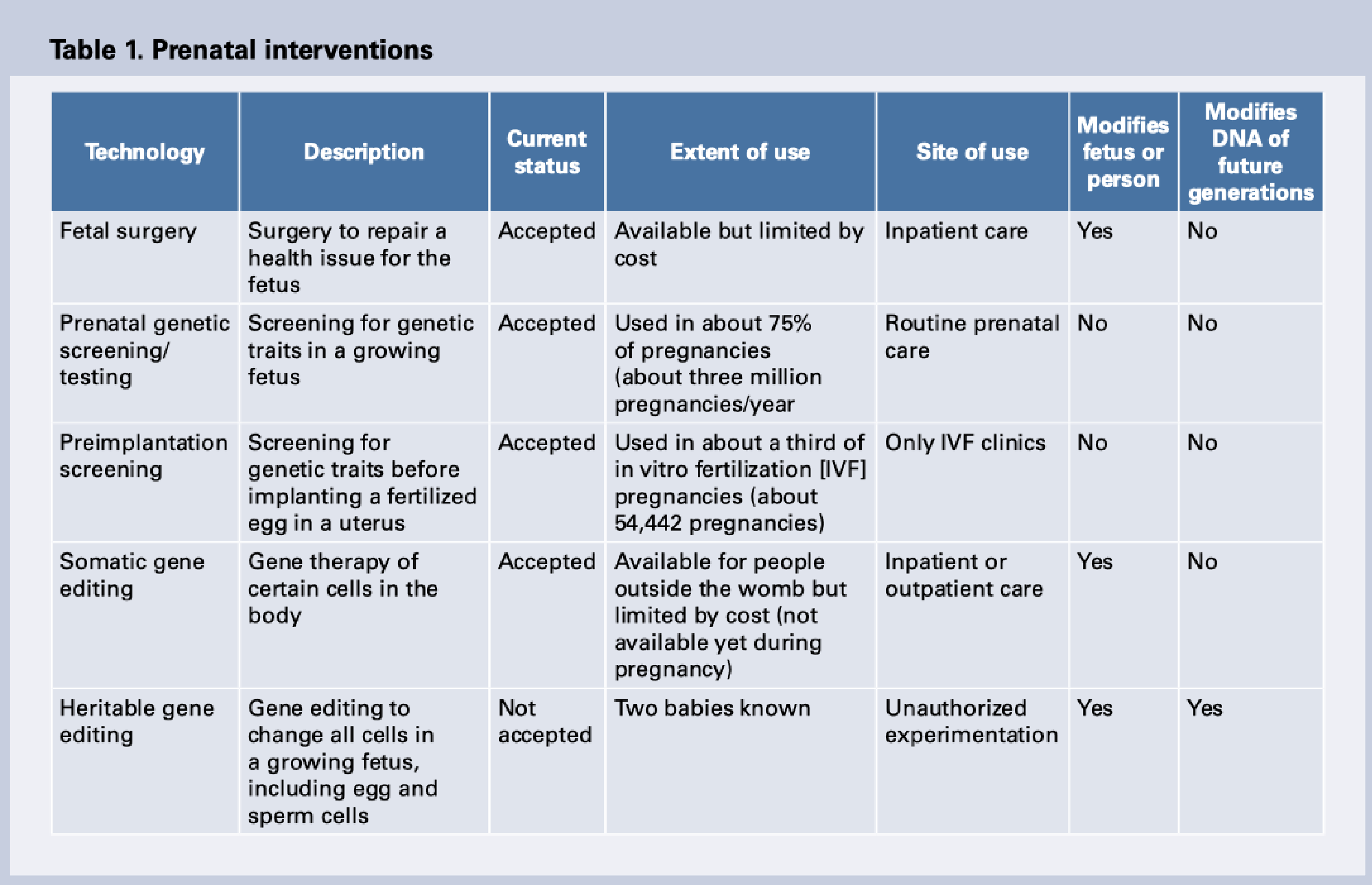
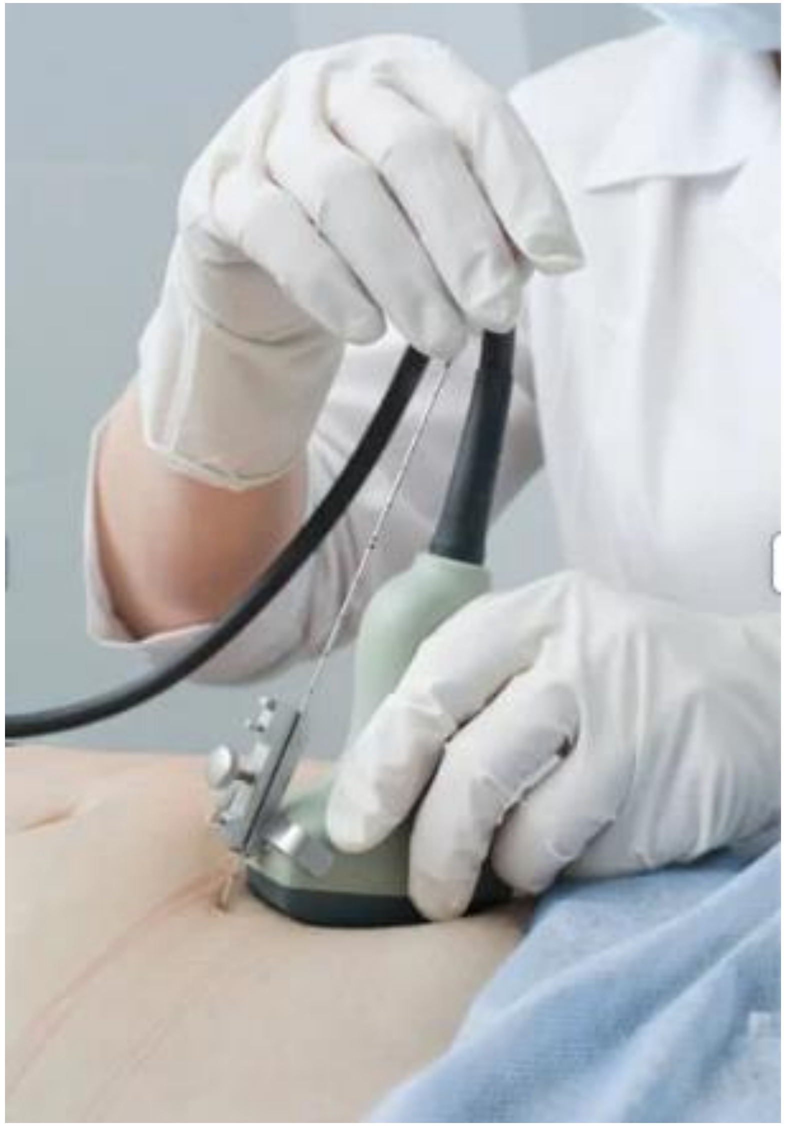


Table 1. Prenatal interventions

Technology	Description	Current status	Extent of use	Site of use	Modifies fetus or person	Modifies DNA of future generations
Fetal surgery	Surgery to repair a health issue for the fetus	Accepted	Available but limited by cost	Inpatient care	Yes	No
Prenatal genetic screening/ testing	Screening for genetic traits in a growing fetus	Accepted	Used in about 75% of pregnancies (about three million pregnancies/year	Routine prenatal care	No	No
Preimplantation screening	Screening for genetic traits before implanting a fertilized egg in a uterus	Accepted	Used in about a third of in vitro fertilization [IVF] pregnancies (about 54,442 pregnancies)	Only IVF clinics	No	No
Somatic gene editing	Gene therapy of certain cells in the body	Accepted	Available for people outside the womb but limited by cost (not available yet during pregnancy)	Inpatient or outpatient care	Yes	No
Heritable gene editing	Gene editing to change all cells in a growing fetus, including egg and sperm cells	Not accepted	Two babies known	Unauthorized experimentation	Yes	Yes

Prenatal Screening and Testing



Prenatal Diagnostic Testing

Procedures that allow for diagnostic fetal genetic testing

- Amniocentesis
  - Performed after 16 weeks gestation
  - Used for prenatal diagnosis since the 1960’s
  - Tests for chromosome conditions
  - Single gene conditions
  - Considered definitive / diagnostic
- Chorionic villus sampling
  - Typically, between 11-14 weeks
  - Testing on placental cells for chromosome and single gene conditions

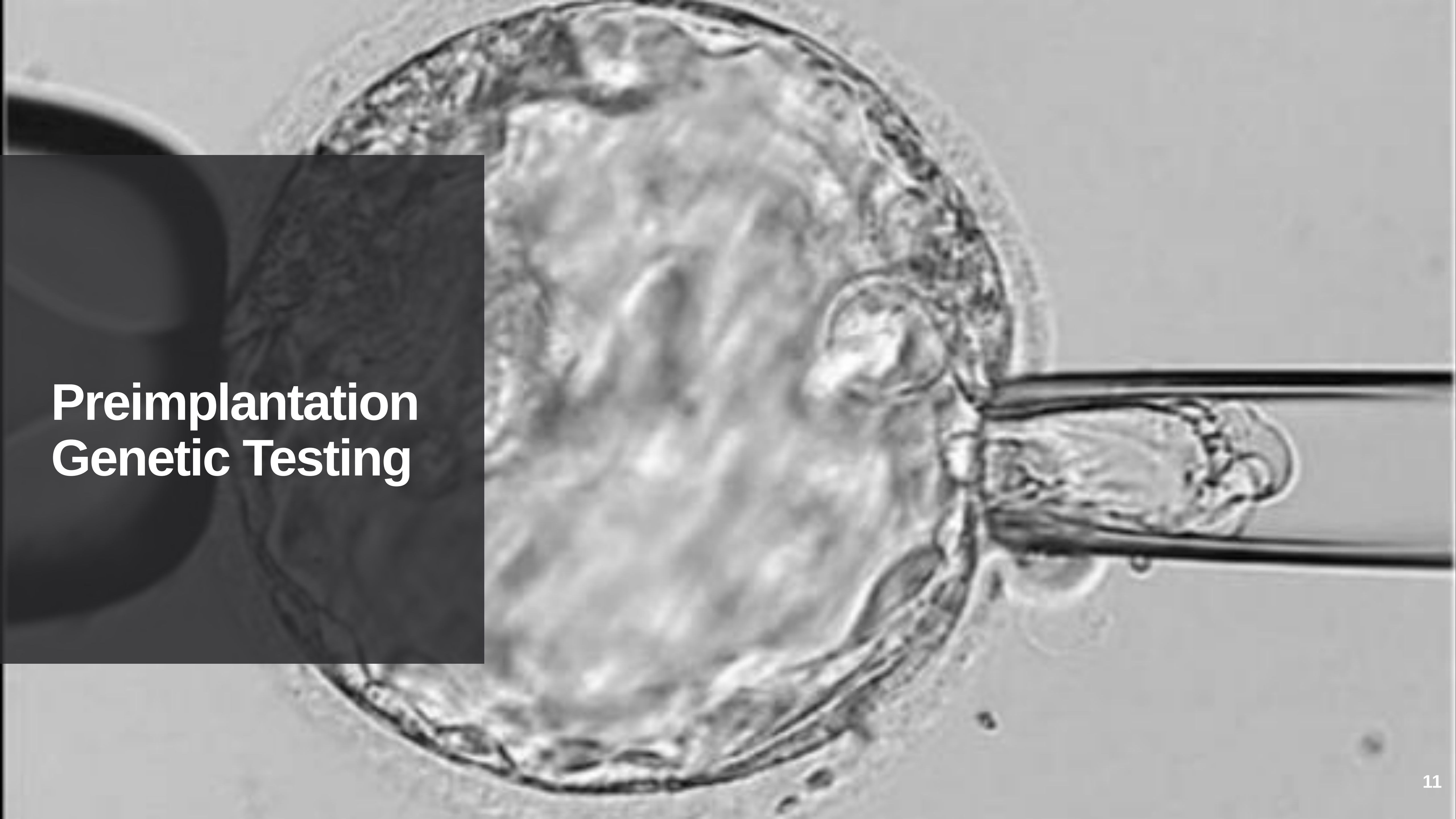
Prenatal Genetic Screening

Blood Tests

- Maternal Serum Screen
- Prenatal cell free DNA screening (NIPT)
  - Chromosome conditions
  - Single gene conditions

Ultrasound

- Nuchal Translucency
- Anatomy Scan
- Markers



Preimplantation Genetic Testing

Preimplantation Genetic Testing

PGT-A

- Aneuploidy
- Screens for chromosome conditions
- First application in 1990 for an X-linked condition
- Increasingly common as a standard add on in IVF

PGT-SR

- Structural rearrangement
- Assesses for unbalanced chromosome rearrangements when a parent is a carrier of a chromosomal rearrangement (e.g., translocation

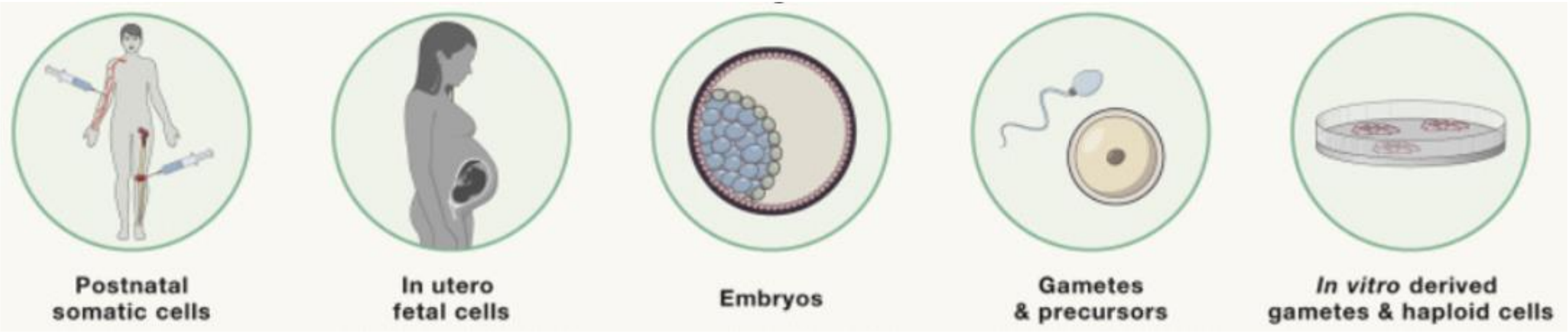
PGT-M

- Monogenic
- Tests for single gene disorder that is carried by one or both parents (dominant, recessive, X-linked)
- Examples:
  - Tay-Sachs
  - Cystic Fibrosis
  - BRCA1
  - Huntington Disease
  - GJB2

PGT-P

- Polygenic
- Uses genetic analysis provide polygenetic scores based on analysis of many genes
- Provides embryo's risk for complex conditions (e.g., heart disease, diabetes, schizophrenia, autism, height, IQ)

Human Genome Editing/ CRISPR: Changing DNA



Targets for Gene Editing

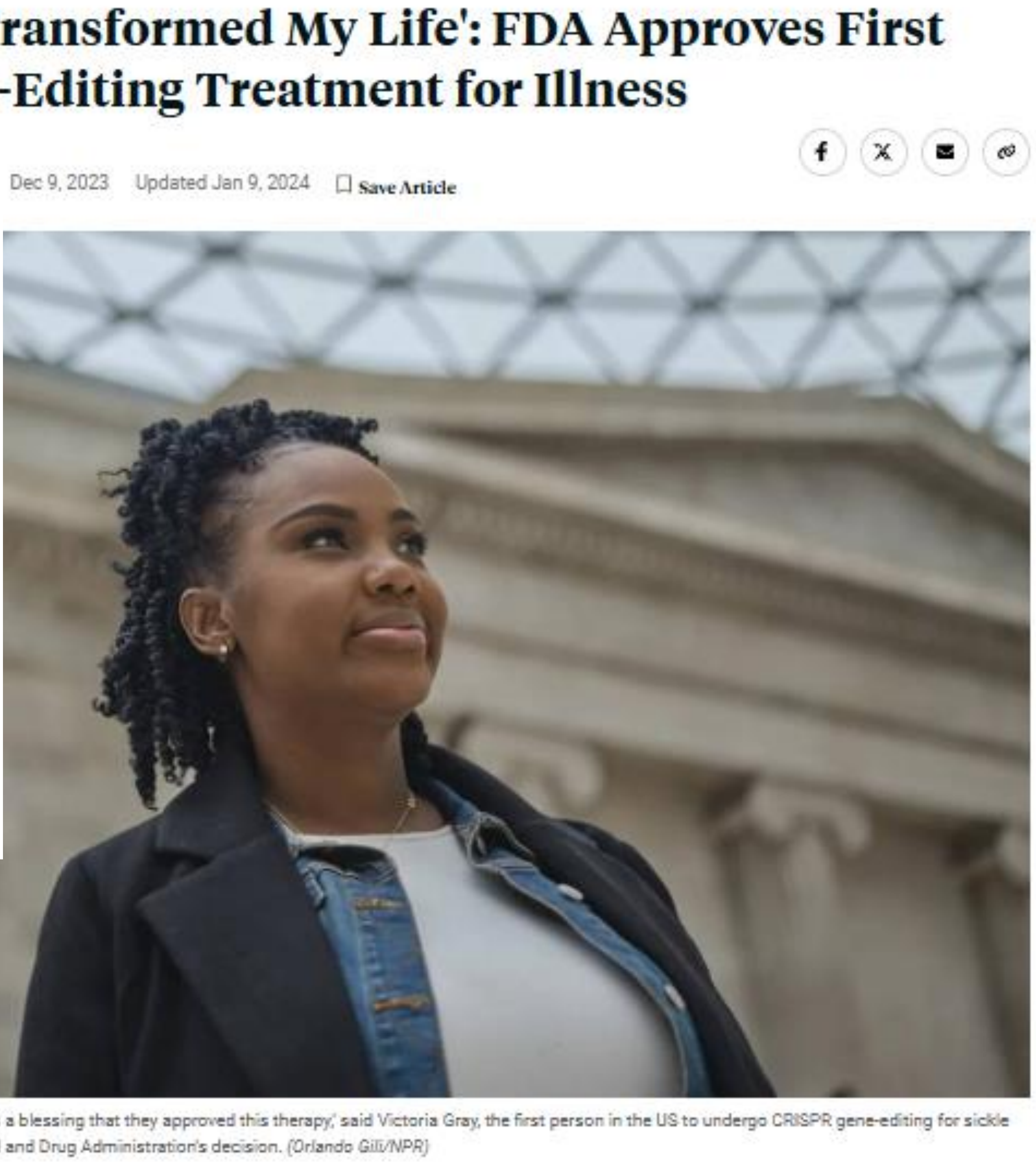
Image From: Heritable human genome editing: Research progress, ethical considerations, and hurdles to clinical practice Turocy, Jenna et al. Cell, Volume 184, Issue 6, 1561 - 1574

FDA NEWS RELEASE

FDA Approves First Gene Therapies to Treat Patients with Sickle Cell Disease

For Immediate Release: December 08, 2023

Today, the U.S. Food and Drug Administration approved two milestone treatments, Casgevy and Lyfgenia, representing the first cell-based gene therapies for the treatment of sickle cell disease (SCD) in patients 12 years and older. Additionally, one of these therapies, Casgevy, is the first FDA-approved treatment to utilize a type of novel genome editing technology, signaling an innovative advancement in the field of gene therapy.



'It's Transformed My Life': FDA Approves First Gene-Editing Treatment for Illness

Dec 9, 2023 Updated Jan 9, 2024 ☐ Save Article

'I'm ecstatic. It's a blessing that they approved this therapy,' said Victoria Gray, the first person in the US to undergo CRISPR gene-editing for sickle cell, of the Food and Drug Administration's decision. *(Orlando Gili/NPR)*

https://www.kqed.org/science/1985709/fda-approves-first-gene-editing-treatment-for-human-illness

https://www.fda.gov/news-events/press-announcements/fda-approves-first-gene-therapies-treat-patients-sickle-cell-disease

World's First Patient Treated with Personalized CRISPR Gene Editing Therapy at Children's Hospital of Philadelphia

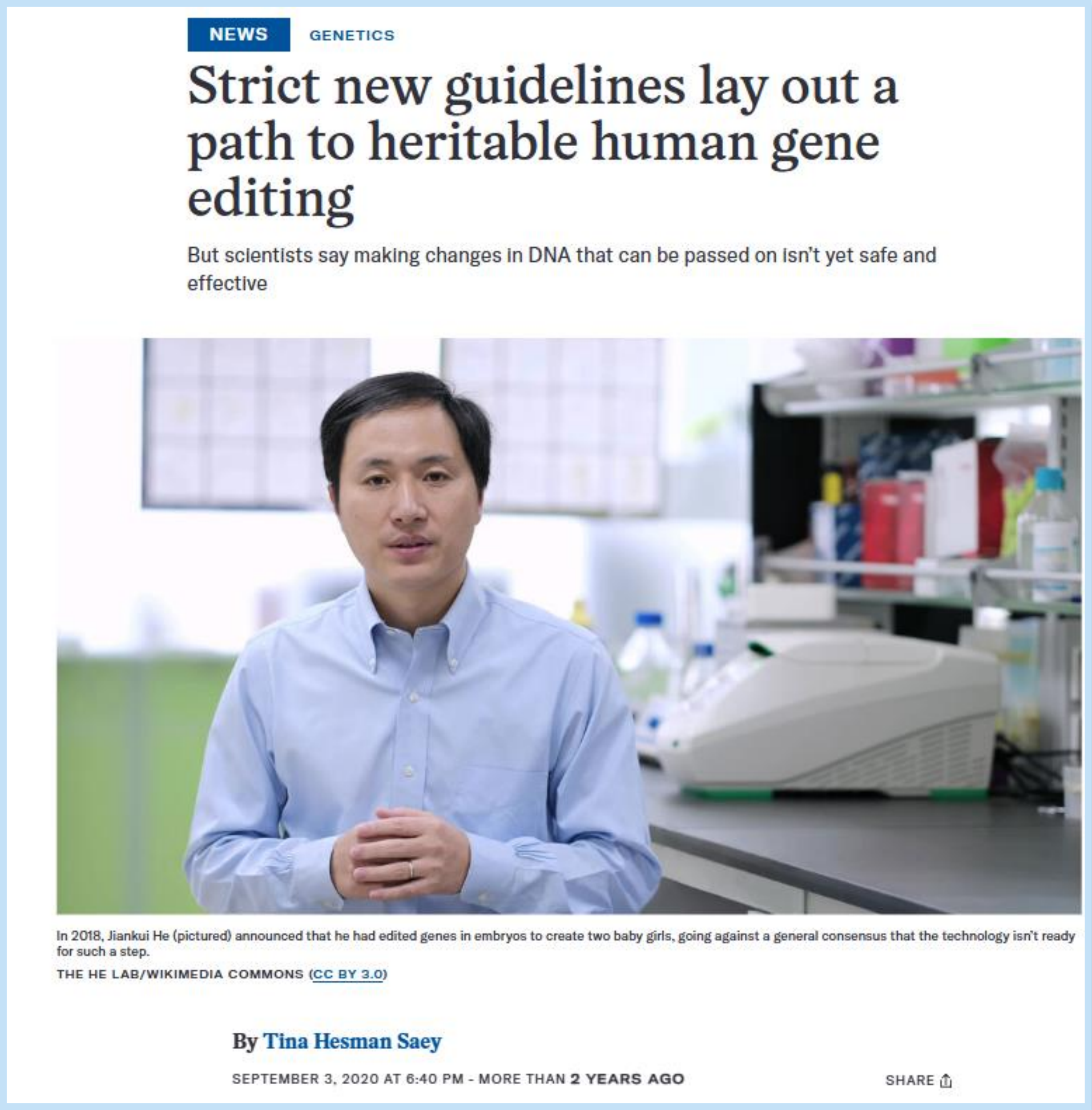
May 15, 2025

KJ's parents, Kyle and Nicole, and his three siblings are looking forward to welcoming him home after a first-of-its-kind personalized gene editing therapy at CHOP.

- Baby KJ ultra-rare genetic condition, called carbamoyl-phosphate synthetase 1 (CPS1) deficiency
- Personalized base editing therapy delivered via lipid nanoparticles to the liver to correct KJ's faulty CPS1 enzyme

https://www.kqed.org/science/1985709/fda-approves-first-gene-editing-treatment-for-human-illness

Heritable Human Genome Editing (HHGE)



NEWS GENETICS

Strict new guidelines lay out a path to heritable human gene editing

But scientists say making changes in DNA that can be passed on isn't yet safe and effective

In 2018, Jiankui He (pictured) announced that he had edited genes in embryos to create two baby girls, going against a general consensus that the technology isn't ready for such a step.

THE HE LAB/WIKIMEDIA COMMONS (CC BY 3.0)

By **Tina Hesman Saey**

SEPTEMBER 3, 2020 AT 6:40 PM - MORE THAN **2 YEARS AGO**

SHARE

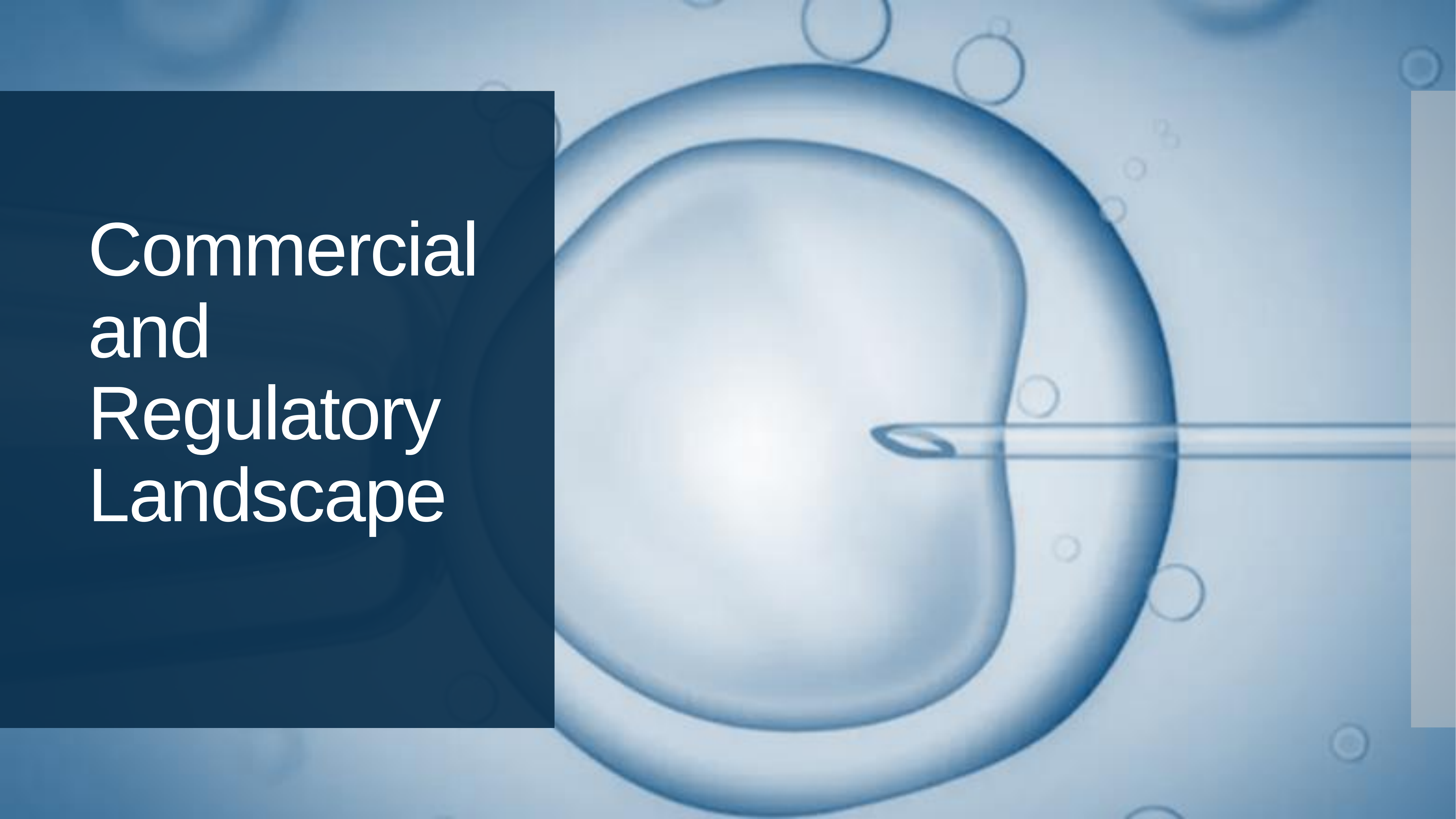
International Commission on the Clinical Use of Human Germline Genome Editing formed after Chinese scientist Jiankui He announced in 2018 two babies resulting from HHGE embryos

HHGE prohibited in 75 countries

US: The Consolidated Appropriations Act, 2023 and 45 CFR 46.204(b) and section 498(b) of the Public Health Service Act (42 U.S.C. 289g(b) (Rep. Connolly 2022

Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (the Oviedo Convention)—signed by 27 countries

https://www.sciencenews.org/article/human-germline-gene-editing-crispr-strict-new-guidelines



Commercial and Regulatory Landscape

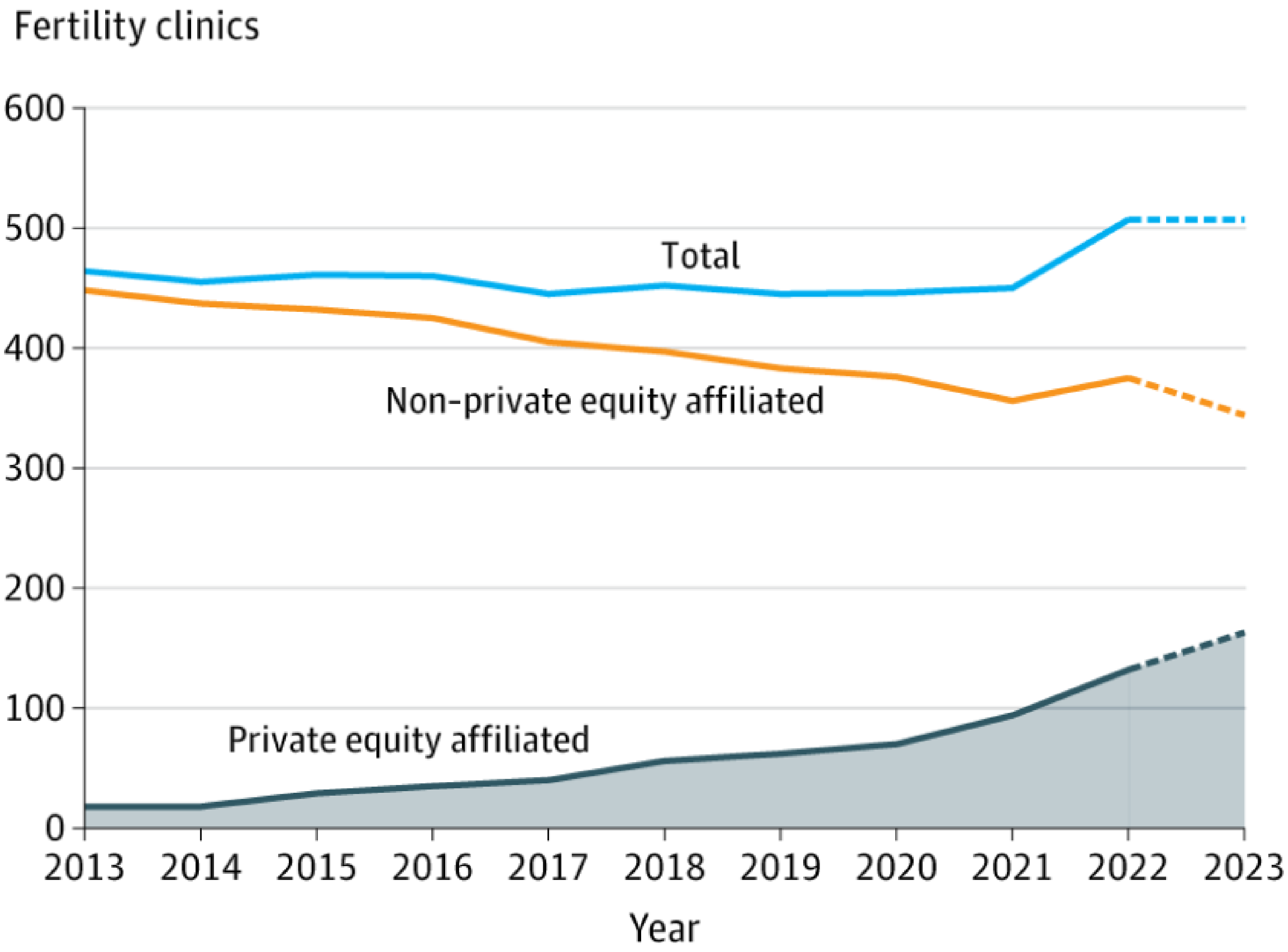
Genetically Engineered Babies Are Banned. Tech Titans Are Trying to Make One Anyway.

Startups funded by some of the most powerful billionaires in Silicon Valley are pushing the boundaries of reproductive genetics, hoping to prevent diseases as well as improve the chances for a high IQ and other preferred traits

Regulatory Gaps in Assisted Reproductive Technologies

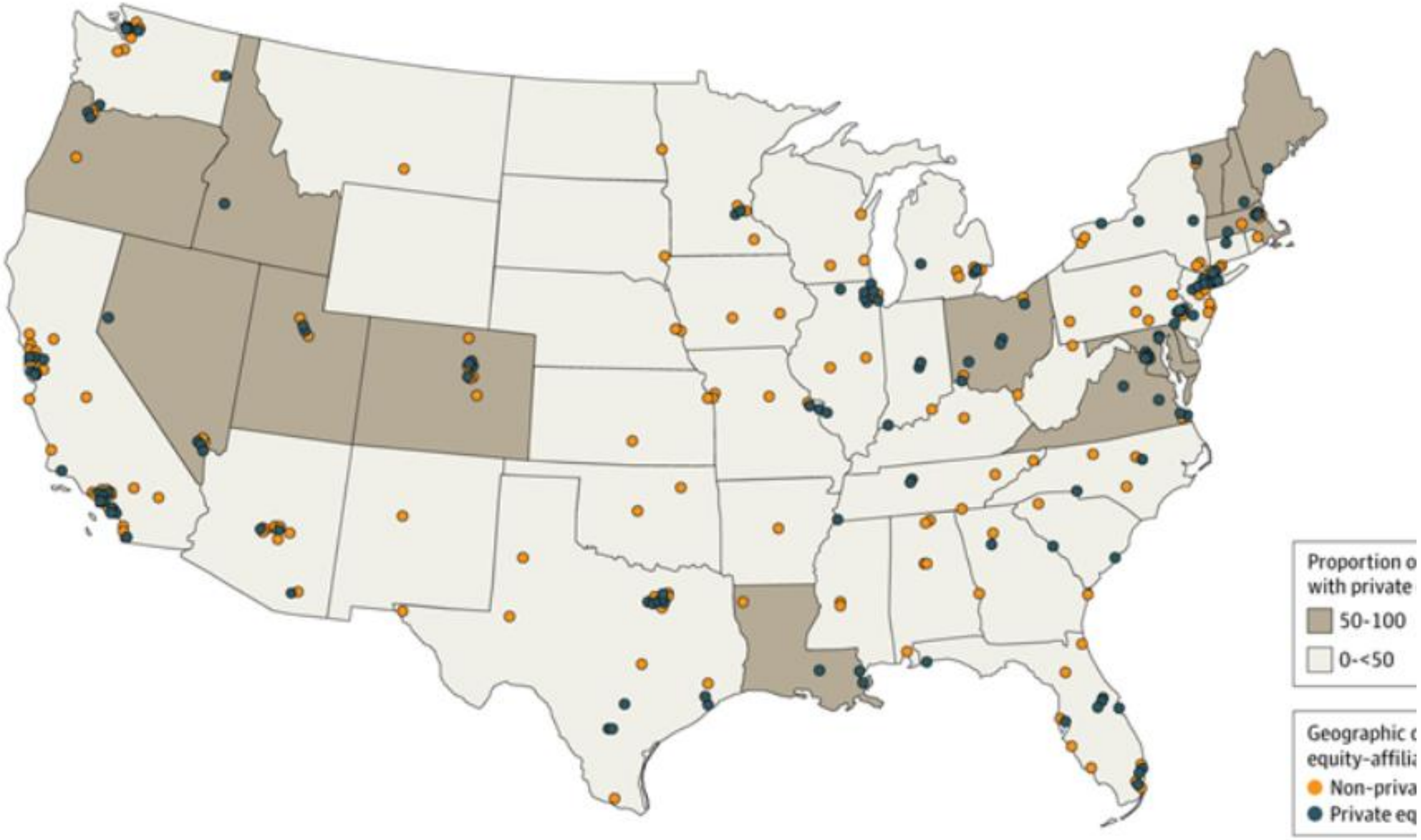
- The Society for Assisted Reproductive Technology (SART) is an affiliate group of the American Society for Reproductive Medicine that accredits and oversees IVF clinics.
- Gaps in oversite with laboratory developed tests
- Much of ART is not covered by insurance
- Vulnerable patient population
- Profit interests of the providers

IVF clinics are rapidly being acquired by Private Equity



Private equity–affiliated fertility clinics performed ~ 63% to 100% of all IVF cycles in CO, DE, ID, LA, ME, MD, MA, NV, NH, Ohio, OR, UT, VT, and VA in 2023

Figure 2. Geographic Distribution of US Fertility Clinics Affiliated With Private Equity Firms



This map provides the locations of the 507 clinics that reported data to the Centers for Disease Control and Pr

Ethical concerns

Current landscape of reproductive genetics and causes for concern

Quick definitions:

- Overton Window
- “Positive” Eugenics/ “Negative” Eugenics
- Pronatalism
- Illiberal or techno pronatalism

Diagnosis Experiences: Journal of Community Genetics

167 Responses (2016-2021)

OF THE 167 PATIENTS IN THIS STUDY, OVER 50% DESCRIBED A NEGATIVE EXPERIENCE

THE ODDS OF HAVING A NEUTRAL/POSITIVE DIAGNOSIS EXPERIENCE WERE ABOUT 18.0 TIMES GREATER FOR THOSE PATIENTS WHOSE PHYSICIANS ADHERED TO ALL SEVEN SOCIAL RECOMMENDATIONS.

THE ODDS OF HAVING A POSITIVE/NEUTRAL SCREENING EXPERIENCE WERE 11.4 TIMES GREATER FOR THOSE PATIENTS WHOSE PHYSICIANS ADHERED TO BOTH EMOTIONAL RECOMMENDATIONS (NOT SAYING "I'M SORRY" OR CONVEYING THE DIAGNOSIS AS BAD NEWS").

Diagnosis Experiences: Disability and Health Journal

242 Responses (2016-2021)

OBs most likely to discuss medical issues (64%) & reproductive options (76%)

Less than 40% of OBs discussed supports and services and life outcomes.

61% of OBs delivered the diagnosis as bad news or said “I’m sorry.” Measure for implicit bias.

OBs with implicit bias significantly less likely to provide more comprehensive prenatal care, information about DS, life outcomes, advocacy organizations & available supports and services

51% of unbiased OBs gave patients accurate, up-to-date, and balanced resources about DS while only 17% of biased OBs did so.

Almost 1/10 described explicit bias.

Embryo Screening and IVF – Who decides?

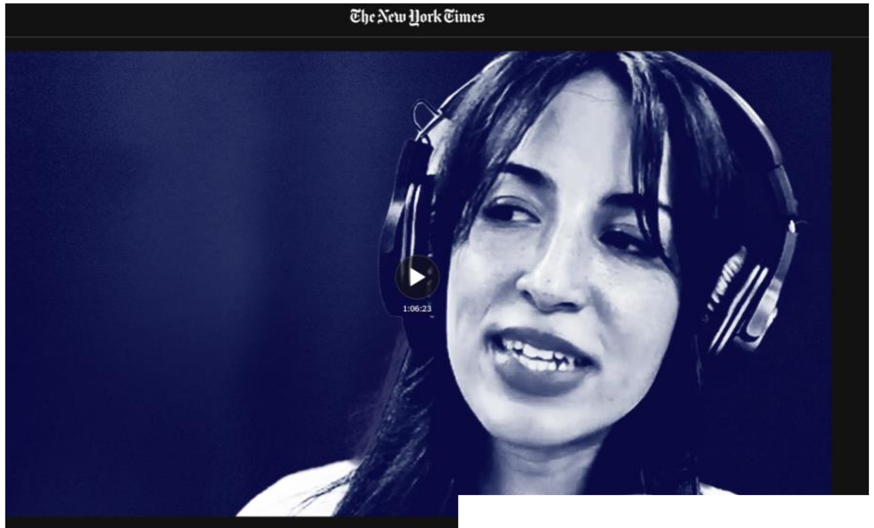
Technology is not value neutral— what if Deaf people want to genetically engineer for Deaf children/population? (Teresa Blankmeyer Burke in Genetics and Society, 2022)

Current Concerns

Expanded Embryo Screening

- Trying to open the Overton window to normalize embryo testing for common conditions and attributes such as height and IQ.
- Often based on flimsy science
- Aggressive marketing
- Companies: Orchid, Genomic Prediction, Nucleus Genomics, and more

“Sex is for fun, Orchid and embryo screening is for babies.”



Silicon Valley Wants
Optimize Your Childr

For as little as $2,500, you can choose you

August 7, 2025

Current Concerns

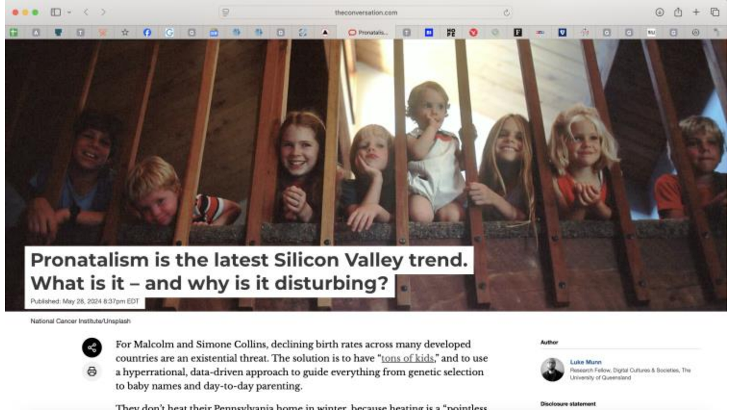
- Supported by Silicon Valley
- Funding by Peter Thiel, Sam Altman, Brian Armstrong
- Allegedly utilized by Elon Musk and Malcolm and Simone Collins
- *“Better babies. Smarter babies.”*

PERSPECTIVE

Tech Oligarchs and the Rise of Silicon Valley Pronatalism

MAREN BEHRENSEN / JUL 2, 2025

This post is part of a series of contributor perspectives and analyses called "The Coming Age of Tech Trillionaires and the Challenge to Democracy." Learn more about the call for contributions here, and read other pieces in the series as they are published here.



Pronatalism is the latest Silicon Valley trend. What is it – and why is it disturbing?

Published: May 28, 2024 8:37pm EDT

National Cancer Institute/Unsplash

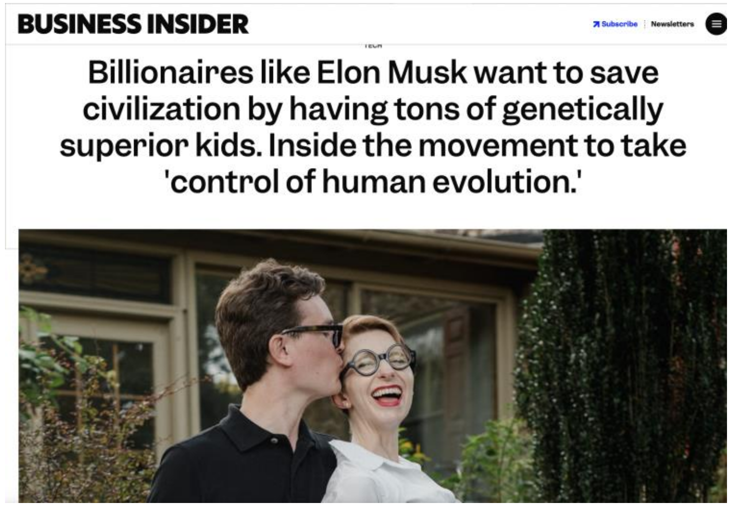
For Malcolm and Simone Collins, declining birth rates across many developed countries are an existential threat. The solution is to have “tons of kids,” and to use a hyperrational, data-driven approach to guide everything from genetic selection to baby names and day-to-day parenting.

They don’t heat their Pennsylvania home in winter, because heating is a “pointless

Author

Luke Munn
Research Fellow, Digital Cultures & Societies, The University of Queensland

Disclosure statement



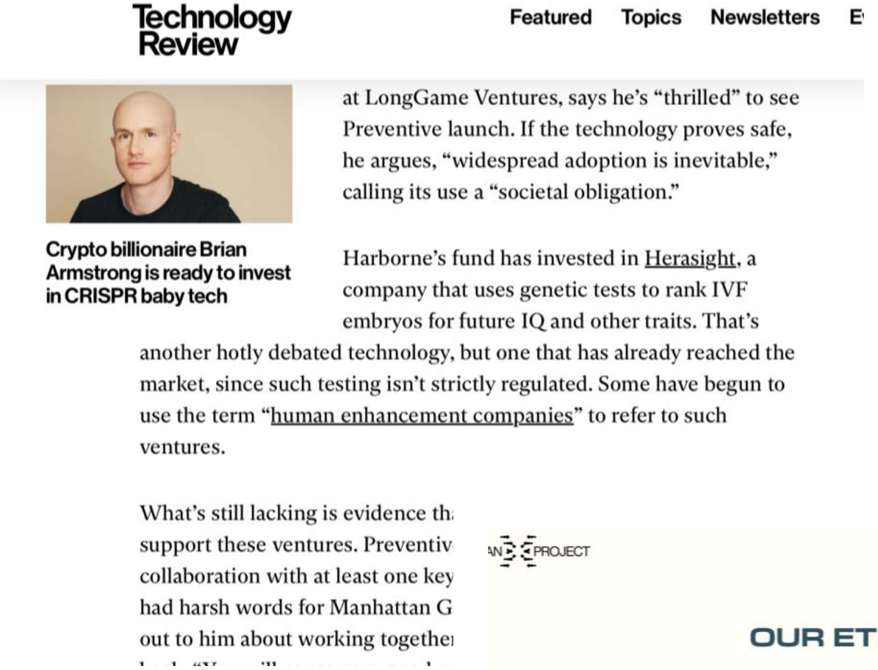
BUSINESS INSIDER

Billionaires like Elon Musk want to save civilization by having tons of genetically superior kids. Inside the movement to take 'control of human evolution.'

Concerns on the Horizon

Commercialization of Heritable Human Genome Editing

Companies: Manhattan Genomics, Bootstrap Bio, Preventative



Crypto billionaire Brian Armstrong is ready to invest in CRISPR baby tech

at LongGame Ventures, says he's "thrilled" to see Preventive launch. If the technology proves safe, he argues, "widespread adoption is inevitable," calling its use a "societal obligation."

Harborne's fund has invested in Herasight, a company that uses genetic tests to rank IVF embryos for future IQ and other traits. That's another hotly debated technology, but one that has already reached the market, since such testing isn't strictly regulated. Some have begun to use the term "human enhancement companies" to refer to such ventures.

What's still lacking is evidence th
support these ventures. Preventiv
collaboration with at least one key
had harsh words for Manhattan G
out to him about working togethe

OUR ETHICS STATEMENT

1. Prevention is the best and most affordable treatment
2. Ethics should be driven by reducing human suffering
3. Our responsibility is to deliver options to patients
4. Data should drive regulatory approval

Manhattan Project was founded with the mission to end genetic disease and alleviate pain and suffering. Inherited genetic diseases caused by

Applying the Disability Lens

Scientists who use CRISPR could see editing genes such as ours out of the gene pool as entirely uncontroversial. But our genetic conditions are not simply entities that can be clipped away from us as if they were some kind of a misspelled word or an awkward sentence in a document. We are whole beings, with our genetic conditions forming a fundamental part of who we are. (Garland-Thomson and Sufian 2021)

Advocacy Organization Statement

“The Autistic Self Advocacy Network (ASAN) sees no disease or condition as an appropriate target for human germline genome editing due to the potential societal and ethical implications of widespread use of the technology.”

“However, germline genome editing has an impact not just on the individual person with a disability but also upon future generations.”

“ASAN neither endorses nor condemns the use of gene therapy or non-heritable genome editing. There are disabilities – such as certain kinds of cancer – in which there is a general consensus by people with the disability that genome editing is permissible” (ASAN, 2019).

https://autisticadvocacy.org/2019/10/asan-comments-on-the-clinical-use-of-human-germline-genome-editing/

Eugenic Implications

“Rebecca Cokley's opinion of the gene-editing technology CRISPR can be distilled into one word.

*‘**It's eugenics**,’ she says, referring to the pseudoscientific movement inspired by Darwin's theory of natural selection and embraced by Nazi Germany and others to weed out "undesirable" traits and even whole races and ethnicities.*

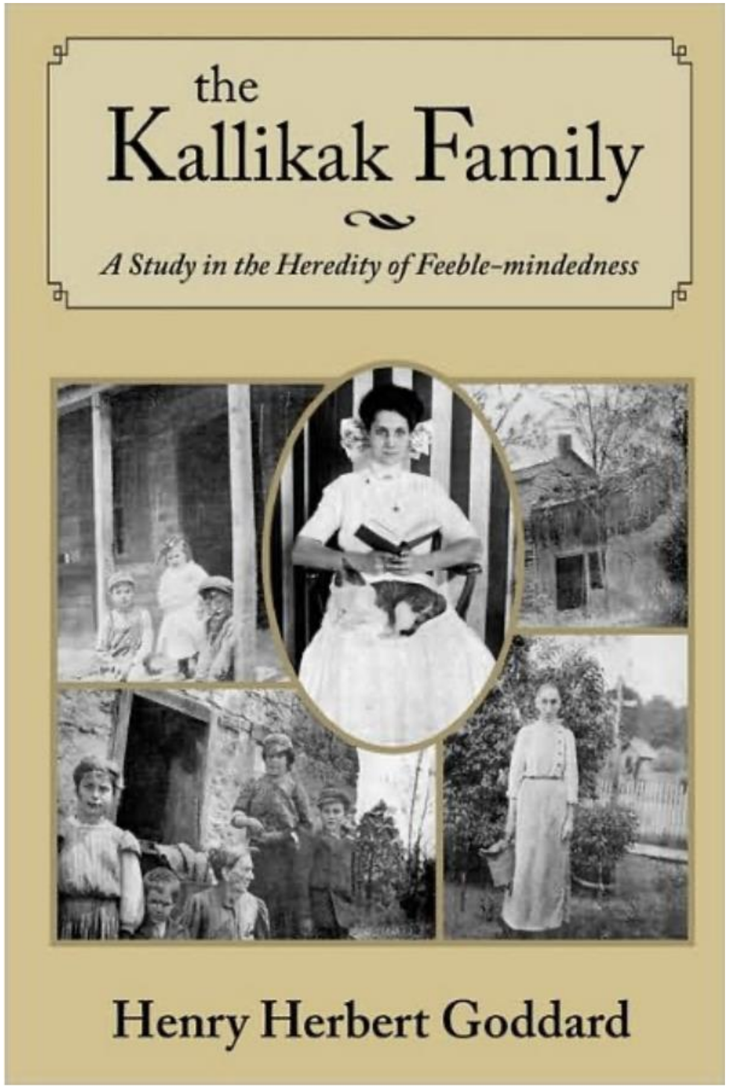
While Cokley [who was born with achondroplasia and works as the Disability Rights Program Officer at the Ford Foundation in New York] was in labor with her third child, who is of typical height, she overheard a doctor in the room suggest that Cokley be sterilized.

‘They want to edit people like us out,’ she says.

That's one reason why Cokley views CRISPR, the gene-editing technology, as an existential menace."

https://www.webmd.com/children/story/centerpiece-crispr-sidebar

History of Eugenics



Eugenics used to be incredibly popular. We can't let that happen again. | Cold Spring Harbor Laboratory

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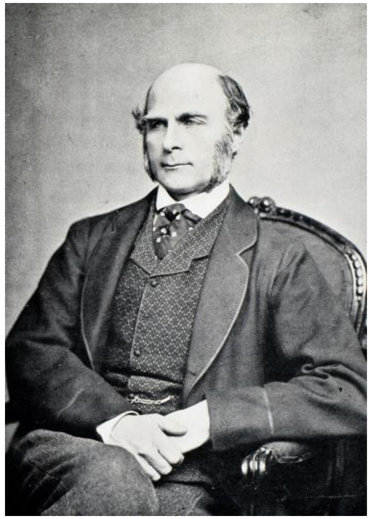
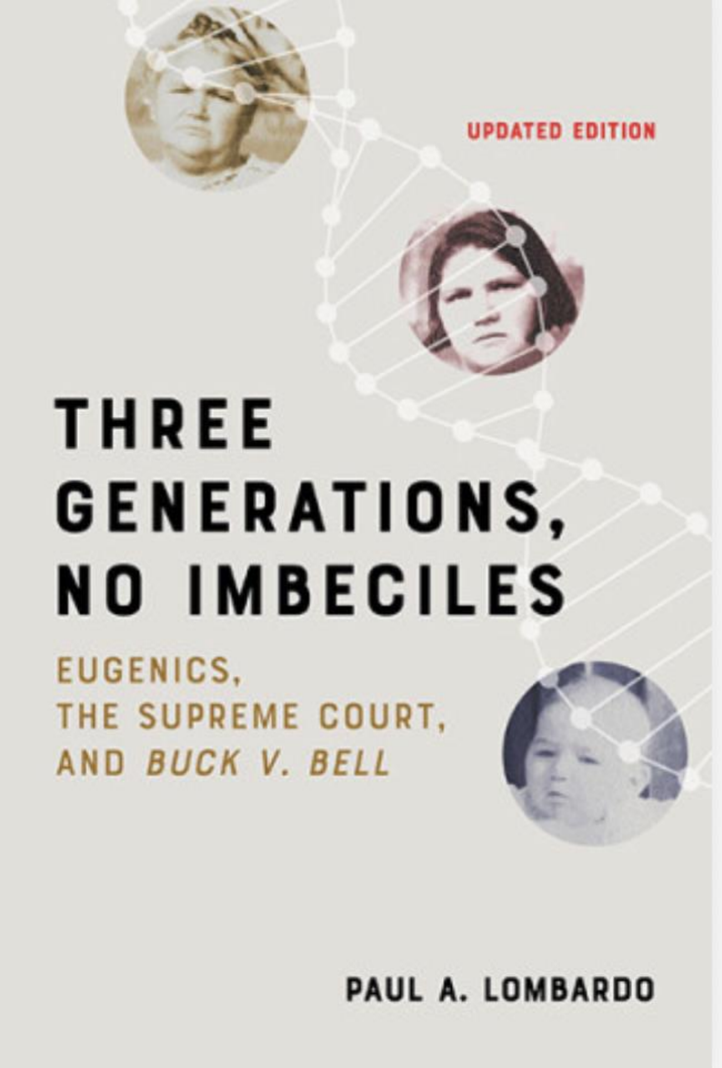


History of Eugenics

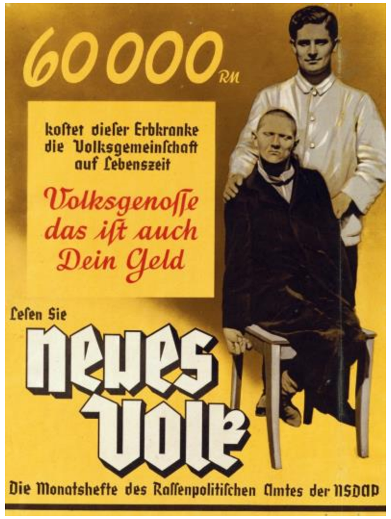


UPDATED EDITION

THREE GENERATIONS, NO IMBECILES

EUGENICS, THE SUPREME COURT, AND *BUCK V. BELL*

PAUL A. LOMBARDO



Group Brainstorming Question:

Greatest concern for you about reprotech?

Ethical Issues to Address

Procedural Justice: Excluding people with disabilities from decision-making

- People with disabilities have not been sufficiently included in the International Summit on Human Gene Editing held by the National Academy of Sciences and the National Academy of Medicine

Relational individual and community solidarity: Seeking to eradicate segments of the population based on ableist perceptions of disability

Non-malfeasance (No harm): The instability and inaccuracy of the technology

Distributive Justice: Likely disparities in health coverage and access

Privacy: Genetic security

Major Ethical Concerns

Bioethicist Tom Shakespeare writes, *“To ‘fix’ a genetic variation that causes a rare disease may seem an obvious act of beneficence. But such intervention assumes that there is robust consensus about the boundaries between normal variation and disability. Contrary to the prevailing assumption, most people with disabilities report a quality of life that is equivalent to that of non-disabled people.”* (Shakespeare 2015)

Federal Policy Priorities on Prenatal Interventions & Disability Equity

Maintain safeguards: Prohibit human germline gene editing for reproduction; uphold embryo research funding restrictions.

Center disability equity: Establish a disability equity fund (excise tax–based) to support advocacy, clinician training, accurate information, and public education.

Strengthen oversight: Expand FDA regulation of prenatal testing, LDTs/NIPS, ART, and marketing claims; enforce conflict-of-interest transparency.

Invest in informed decision-making: Fund public education, community forums, and data collection on accuracy, outcomes, and disability impact.

Protect families: Expand Medicaid, IDEA, ADA, GINA, and comprehensive pregnancy coverage to prevent discrimination or coercion.

Expand access & workforce: Pass key legislation (GC Services Act, HEADs UP, VALID Act); reimburse genetic counseling; support disability-inclusive career pipelines.

Ensure global accountability: Participate in international governance to prevent unethical heritable genome editing and medical tourism.

Group Brainstorming Question: Most promising collaborative policy strategy?

Center for Genetics in Society (Katie Hasson)

Research by Daphne Martschenko

GSF Blog: Gene Cuisine

GSF Podcast: CODED: Genetics

Julia Black: Tech Won’t Save Us

Recommended Resources

CONTACT INFORMATION

Katie Stoll, MS, CGC
kstoll@geneticsupport.org

Stephanie Meredith, MA, DrPH
smeredith@geneticsupport.org

Current landscape of reproductive genetics and causes for concern

Quick definitions:

- Prenatal Screening and Diagnostic Testing
- Embryo Screening (PGT-M/PGD) and IVF
- Polygenic embryo screening (PGT-P) and IVF
- CRISPR Technology
- In Vitro Gametogenesis
- Overton Window
- “Positive” Eugenics / “Negative” Eugenics
- Pronatalism
- Illiberal or techno pronatalism