\equiv

 $\boxed{2}$

How overturning Roe v. Wade restricts the power of genomics

The overturning of Roe v. Wade and resulting legal barriers are already restricting screening and reproductive options.



by Bethany Zettler

On June 24, 2022, the U.S. Supreme Court overturned Roe v. Wade, which guaranteed the constitutional right to abortion for almost 50 years. This decision has now been handed back to the states, resulting in a patchwork of legal protections and restrictions across the country.

The Dean of Harvard Medical School and president and CEO of Mass General Brigham have issued statements on this difficult topic, recognizing that individuals hold their own personal opinions around pregnancy termination. These organizations remain committed to providing high-quality, safe, and equitable access to full reproductive health services under Massachusetts law, and respect the medical decisions made by patients and clinicians.

Leading genetics professional societies have released statements opposing this ruling from a medical and scientific perspective. The National Society of Genetic Counselors (NSGC) emphasizes that "access to genetic information promotes informed decision-making . . . including sustained access to abortion care." The American Society of Human Genetics (ASHG) warns that abortion restriction "denies our patients the ability to make informed decisions about their healthcare based on prenatal imaging or diagnosis." The American College of Medical Genetics (ACMG) asserts that "access to safe and legal termination of pregnancy for genetic disorders or congenital anomalies that are diagnosed prenatally is an important option." These societies also highlight that restricting comprehensive reproductive care will impact marginalized groups disproportionately and worsen existing inequities.







Genomes2People **48** Followers

The G2P Research Program (www.genomes2people.org) is focused on the judicious integration of genomic research into personalized medicine & clinical practice.



More from Medium

Jonathan Day When you lose them.

elise.sierrah

During this era of so-called love, love can be man...



()) Lintang Seni 零...

My Fondness for Werder and Bremen



Help Status Writers Blog Careers Privacy Terms About Knowable

Why are these organizations so adamant that overturning *Roe v. Wade* is bad for our patients and the field of genetics?

First, this decision impacts the practice of genetic counseling. Adhering to the medical standard of care, prenatal genetic counselors (GCs) offer screening during pregnancy for a handful of conditions that can drastically affect an unborn child and the future of an entire family. For example, trisomy 13 is a genetic chromosomal abnormality that occurs randomly at conception and causes severe birth defects, and fewer than 10% of affected children survive the first year of life. Tay-Sachs disease is a recessive genetic disorder in which affected babies develop neurodegeneration within their first few months and die in early childhood. After a positive screening test and subsequent diagnosis, GCs and physicians have historically offered two essential options: continuing the pregnancy and preparing for an affected child, or stopping the pregnancy. In some situations, a third option of placing a child with special needs for adoption is also available. Families deserve the chance to screen for these life-limiting conditions and other serious disorders in order to make informed decisions.

Since the Human Genome Project was completed, the power of genomics has expanded to enable screening for thousands of severe recessive diseases, offering parents the best chance to have a healthy child. In the Mass General Brigham <u>Preventive Genomics Clinic</u>, we offer genome sequencing for prospective parents to screen for nearly 6,000 genes associated with genetic health risks. Nearly everyone has recessive variants hidden in their DNA. If two parents carry harmful variants in the same gene, each pregnancy has a 25% chance to be affected with a recessive genetic disease, many of which are serious and begin in early childhood. Historically, these families have had a range of reproductive options. For example, preimplantation genetic testing (PGT) leverages the power of in vitro fertilization (IVF) for parents seeking to have an unaffected child. Embryos are created outside of the body and screened for a specific genetic condition before being placed in the uterus to start a pregnancy. This option has allowed tens of thousands of families to have healthy children, even if both parents are carriers for the same recessive disease.

Unfortunately, the overturning of *Roe v. Wade* and resulting legal barriers are already restricting screening and reproductive options. Most genetic testing happens <u>during pregnancy</u>, and so genetic conditions are being detected long after the gestational limit for termination in restrictive states. Prenatal GCs are now navigating a <u>gray area of liability</u> around what information is legally acceptable to share with patients, even those who have a fetus affected with a devastating disorder. In restrictive states, new laws have "caused a chilling effect" on what providers feel comfortable saying, and some geneticists are no longer comfortable discussing options like IVF and PGT with families who could otherwise benefit from this technology (personal communication). Legal barriers will also likely impact where scientists and specialized providers choose to work and live, further increasing disparities in access.

Indeed, these restrictions disproportionately affect marginalized groups. Genetics has already been considered "elitist," since testing can come with large out-of-pocket costs and options like IVF with PGT can cost tens of thousands of

dollars. The Turnaway Study found that being denied an abortion increased risk of financial instability by 81%, an effect that persisted for at least five years. Now, imagine that someone is denied an abortion even though the fetus has a severe genetic disorder with lifelong medical needs. The cost of rare diseases, most of which are genetic, is nearly <u>1 trillion dollars annually</u> in the U.S. Patients, insurance payors, and healthcare systems may be financially impacted by this decision for decades.

The evolving legal landscape could also affect genomics research. Federal funding decisions may be impacted, determining what type of research is allowed to progress. At Genomes2People (G2P), we are preparing for challenges with enrollment into genetic research studies, as the overturning of Roe v. Wade further disrupts trust in the government and healthcare systems.

Finally, this decision may hinder efforts to diversify the field of genetics providers, which is currently disproportionately White. One of the main reasons for seeking an abortion is to focus on educational aspirations, and abortion legalization increased <u>college graduation rates</u> among Black women by 9.6%. Becoming a GC or genetics physician requires the privilege of attending college and then graduate or medical school. Lack of abortion access could disproportionately restrict educational attainment of people from marginalized communities, especially in restrictive states that are already underrepresented in the GC workforce.

The goal of G2P research, and much of the genomics revolution, is using our unique DNA to provide meaningful health information, options, and empowerment. Genetic screening before conception and during pregnancy gives prospective parents more insight into how their family may grow. The priority of nearly all parents is a healthy, happy child, and learning that a fetus is nonviable or has a life-limiting genetic condition can be a devastating experience. Genetics providers help real parents navigate these complex emotions and subsequent decision-making, and having safe, comprehensive reproductive options is essential healthcare. The overturning of Roe v. Wade is already impacting medical care and decision-making for expecting families, and will continue to affect their physicial, mental, and financial health for decades. Supporting abortion funds, voting for pro-choice leaders, and advocating within our networks are acts of compassion we can all take to support science, medicine, and healthy families accross the country.

Bethany Zettler is a Genomes2People team member, project manager of The BabySeq Project, and lead genetic counselor for the Brigham Preventive Genomics Clinic. The views represented here are the author's own.

§ (17) 9

(⁽¹⁾) 9 ()

More from Genomes2People



The G2P Research Program (www.genomes2people.org) is focused on the judicious integration of genomic research into personalized medicine & clinical practice.

Apr 29

Unlocking a cosmos of diversity within the profession of genetic counseling

Reaping the full benefits of personalized medicine requires a cadre of genetic counselors as diverse as our patients. We're working on it. by...

Personalized Medicine 4 min read

Share your ideas with millions of readers.

Write on Medium

Jan 25

How Genomic Researchers Can Save Their Participants' Lives

A new report on returning genomic research results to biobank participants makes a strong case for doing more of this — and how not to do it. by...

Genetics 3 min read

G

Oct 21, 2021

Newborn Genome Sequencing: The next step in public health?

For the first time in history, we can treat the underlying cause of some genetic diseases — if we catch them early enough. What does this mean f...

Genetics 4 min read

Jul 29, 2021

Unlocking the Human Genetics of COVID

In an unprecedented international effort, researchers and clinicians tackle the genomics of COVID-19 risk. by Robert C. Green Why does COVID-19 affect some people differently than others? Are some people more likely t...

Covid 19 4 min read

May 25, 2021

Precision Medicine: From Breakthrough to Follow-Through

by Nic Encina Our recent launch of Precision Population Health officially introduced Ariadne Labs into the world of precision medicine. Since bein...

Precision Medicine 7 min read















Try Knowable

 \square^+

 \square^+



 \square^+