

Genetic screening results just got harder to handle under new abortion rules

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Credit: Pixabay/CC0 Public Domain

Ann was 15 weeks pregnant with her fourth child when the results of her prenatal genetic test came back last August. The test suggested that her daughter, whom she and her husband planned to name Juliet, was missing one of her two X chromosomes—a condition called Turner syndrome that can cause dwarfism, heart defects, and infertility, among other complications.

Many people decide to terminate their pregnancies after this diagnosis, a genetic counselor told Ann and her husband. But the counselor had more bad news: In two days, the family would no longer have that option in their home state of Texas. A law, in effect as of Sept. 1, 2021, allows anyone to sue those who assist any person in getting an abortion in Texas after six weeks' gestation—and the state provides a \$10,000 bounty to plaintiffs if they win. The genetic counselor told Ann she could no longer discuss termination with her for this reason.

"At the time I thought, 'It doesn't matter; we're not giving up on this pregnancy,'" said Ann, who asked that only her middle name be used out of concerns about privacy and potential legal repercussions for her medical providers, her husband, or herself under Texas' unclear legal framework. She considered herself pro-life, and the diagnosis still needed to be confirmed through amniocentesis and ultrasound.

But after reading about the condition, she realized how devastating it could be. If Juliet survived birth, which was statistically unlikely, the child would be hospitalized frequently and might need daily hormone shots, costing \$60,000 per year. Ann and her husband began to worry about how having this child would affect their three other children.

The vast majority of abortions occur at or before 13 weeks, and people who seek abortions later than that frequently cite barriers to accessing care or discovery of a medical complication. But Texas' law has effectively banned virtually all abortions in the state because many women don't even know they are pregnant at six weeks. No prenatal tests can diagnose genetic conditions before 11 weeks.

Situations like Ann's will soon happen across the country. The U.S. Supreme Court on June 24 upheld Mississippi's statute that outlaws abortion after 15 weeks, and overturned the 1973 *Roe v. Wade* decision that guarantees the right to abortion. At least half the states are likely to

ban abortion, according to the Guttmacher Institute, a research organization that supports abortion rights.

Before the court's decision, only 10 states with gestational limits on abortion have had exemptions for conditions lethal before or at birth. None allow exemptions for serious but nonlethal conditions. Without such exemptions, people who can neither afford to raise a child with a disability nor travel to a clinic out of state could be left in a difficult spot.

For families who've just learned their child may not survive birth or will have a debilitating condition, such legal issues add one more trauma to an already traumatic decision.

Lauren Westerfield, a prenatal genetic counselor in Houston, said the Texas law has made it impossible for her to fully do her job. She expects that, for that reason, many counselors will choose not to practice in Texas or other states where abortion is now illegal—or soon will be—because of trigger laws launched by the Supreme Court decision.

When patients ask about termination, "I tell them, 'Legally, in Texas, you don't have that option,'" she said. "I don't have words to describe the look that comes over their face when they hear that."

Many patients have no choice but to carry the pregnancy to term. Westerfield estimated at least 75% of her patients who would have terminated their pregnancies have been prevented by the state law since it passed.

Little is known about the outcomes for people unable to terminate a pregnancy with genetic anomalies. But a study that tracked 1,000 women who were turned away from abortion clinics because they were past gestational limits found they were far more likely to fall into poverty and

had worse overall health than those who had gotten abortions.

Laura Hercher, a genetics expert and ethicist at Sarah Lawrence College, worries that restrictive abortion laws will mean genetic disorders will eventually occur almost exclusively among [poor families](#), particularly as [technological advances](#) provide better prenatal diagnoses. Wealthier people could travel to other states for an abortion—or undergo in vitro procedures that screen out embryos with genetic anomalies.

"Ultimately, it will create a situation where one part of the population says, 'This can't happen to me,'" she said—and everyone else who cannot afford that privilege will be stuck without options.

Dr. Brian Skotko, a medical geneticist at Massachusetts General Hospital and an advocate for people with Down syndrome, said lack of education and awareness about genetic conditions is already a problem for people living with these disorders, as well as for parents choosing whether to continue a pregnancy. Prenatal counselors, he said, should provide expectant parents with accurate, up-to-date information about the reality of those conditions so they can make informed decisions.

As prenatal testing has become more common, so too have selective terminations of pregnancies involving genetic conditions. A published review of studies suggests that 67% of pregnancies with a diagnosis of Down syndrome end in abortion.

Among abortion opponents, however, terminating a pregnancy after such a diagnosis is seen as an act of injustice against a weaker party. John Seago, president of Texas Right to Life, called such situations "tragic" but added that "we have to have better answers than 'the only solution is to cause the death of the child.'"

Seago said his organization supports a Texas bill known as the Preborn

Non-Discrimination Act, which would require genetic counselors to inform patients about prenatal palliative care services and support groups to help them carry the pregnancy to term. Right now, he said, "the only voices" that pregnant people hear in medical conversations are pro-abortion.

For Ann in Texas, there were no simple answers. A week after the initial test results, an amniocentesis and an ultrasound to see Juliet's anatomy confirmed the worst: Juliet had a severe heart condition, muscular problems, and other complications.

Ann began joining Turner syndrome support groups and reading about people living with the disorder. Many, she learned, die from heart conditions in their 20s and 30s. She also saw a video of a little girl with Turner syndrome getting her daily hormone injection. The child was screaming in pain.

That was when Ann decided to end the pregnancy, fearing the pain Juliet would have experienced every day. "This decision is out of love," she said. "It's taking the pain away from them by experiencing it yourself."

She made an appointment with a clinic in Colorado in late September. Because the [pregnancy](#) was 19 weeks along, the procedure would be complicated and expensive, requiring her to stay in Colorado for a week.

She knows she was fortunate to have the option to travel, which many people in her situation could not do. "I was really angry, because I felt like this was something that should be done by your doctor and your hospital," she said.

Soon after the amniocentesis results, she began experiencing severe cramping. But she didn't tell the obstetrician she'd been seeing, worried that the practice would face the choice of dropping her as a patient or

being sued under Texas law for abetting an abortion.

Seago said the law applies only to abortions performed within Texas; helping someone obtain an abortion outside the state would not be a crime.

Still, Hercher and others worry that this kind of fear and uncertainty may end up hurting those who are pregnant. Although Texas' and most other states' laws provide exemptions to protect a mother's health, it's unclear how this will be interpreted in each state.

Ann had her [abortion](#) on Sept. 28—a month after the initial diagnosis had turned the family's joy into a nightmare. Before having Juliet cremated, she held her daughter.

In recent months, she has joined [support groups](#) for mothers who have terminated their pregnancies for medical reasons. Besides providing a loving and understanding community, they are the only people who can fully understand her family's situation.

"At no point does it feel like a decision," she said. "The diagnosis is a decision that's been made for you."

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