

BIOETHICS NEWS STORIES

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“When They Warn of Rare Diseases, These Prenatal Tests Are Usually Wrong” by Sarah Kliff and Aatish Bhatia, *The New York Times*, January 1, 2022

The tests initially looked for Down syndrome and worked very well. But as manufacturers tried to outsell each other, they began offering additional screenings for increasingly rare conditions. The grave predictions made by those newer tests are usually wrong, an examination by *The New York Times* has found. (<https://tinyurl.com/ym4u7zpy>)



“Study Raises Questions About Popular Genetic Test for ‘Abnormal’ Embryos” by Azeen Ghorayshi, *The New York Times*, April 20, 2022

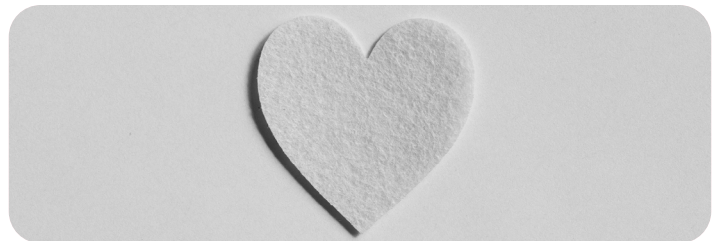
The genetic test, called preimplantation genetic testing for aneuploidy, or PGT-A, has, over the last two decades, become a standard add-on to already pricey I.V.F. procedures. But the test, which can cost anywhere from \$4,000 to \$10,000, has become controversial over the years as studies have cast doubt on whether it increases birthrates from I.V.F. at all. (<https://tinyurl.com/mpanjfdb>)

A *New York Times* report and a study published in the journal *Human Reproduction* add to concerns that prenatal and embryonic genetic tests do not predict whether a child will be healthy or not. The *New York Times* looked at the five most popular genetic conditions that are tested for using non-invasive prenatal tests, or NIPT. Unlike risky prenatal tests that require a cell sample either from the embryo or from the placenta, NIPT only requires a blood sample from the mother. The test works well for Down syndrome, but for other conditions, the test has, on average, an 85% false-positive rate. The FDA has since issued a warning that these tests are not cleared or approved by any regulatory body.¹

The *Human Reproduction* study looked at the pre-implantation genetic test that is used to evaluate whether embryos made through *in vitro* fertilization have chromosomal errors. Typically, any “abnormal” embryos are not implanted; however, these “abnormal embryos” can result in a normal baby. This means many parents have made decisions based on the false assumption that abnormal embryos will not result in a pregnancy or a healthy child.

“In 1st, US Surgeons Transplant Pig Heart into Human Patient” by Carla K. Johnson, *Associated Press*, January 10, 2022

In a medical first, doctors transplanted a pig heart into a patient in a last-ditch effort to save his life and a Maryland hospital said Monday [January 10] that he’s doing well three days after the highly experimental surgery. (<https://tinyurl.com/5f6r7a3d>)



“US Man Who Got 1st Pig Heart Transplant Dies after 2 Months” by Luran Neergaard and Carla K. Johnson, *Associated Press*, March 9, 2022 (<https://tinyurl.com/4hxx523e>)

David Bennett, 57, died Tuesday at the University of Maryland Medical Center. Doctors didn’t give an exact cause of death, saying only that his condition had begun deteriorating several days earlier.

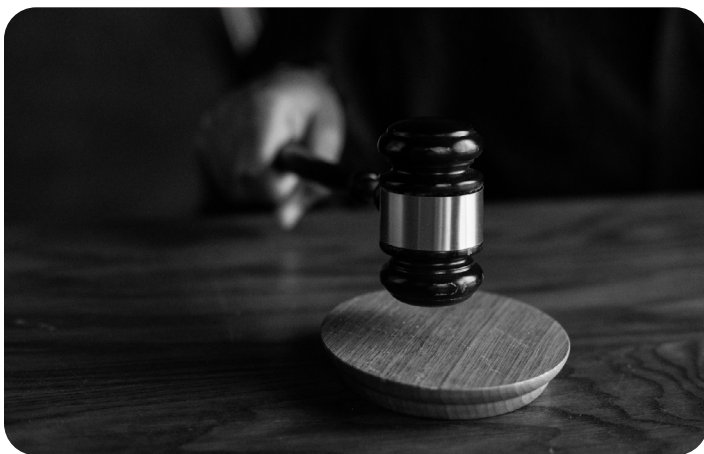
David Bennett, who underwent an experimental pig-to-human heart transplant, died two months after receiving the transplant; however, doctors say that the transplanted heart was doing well. They are unsure if the presence of an animal virus in Bennett’s tissues had anything to do with his decline or if it was due to Bennett’s multiple health issues. Bennett had advanced heart failure and did not qualify for a (human) transplant because he was “non-compliant.” An article in *Wired*’s ideas section outlined the ethical issues surrounding non-compliance as a disqualification for being on the transplant list, yet still qualifying for a highly experimental procedure.²

Past animal-to-human transplantations have failed because the human body rejects the animal organ. However, for Bennett’s procedure, doctors used pigs that were genetically modified so the human immune system will not attack the organ. Furthermore, Bennett received a new immunosuppressant drug, and the heart was transported in a special bath of water, hormones, and dissolved cocaine.

“Are We About to Cure Sickle-Cell Disease?” by Dhruv Khullar, *The New Yorker*, March 22, 2022

More than a century after sickle-cell disease was first diagnosed, advances in gene therapy are poised to make it not just treatable but curable. But technology is only one part of medicine. The treatments won't be cheap, and many of the people who need them the most are on the fringes of a medical system that has marginalized them. (<https://tinyurl.com/mr2e9ppf>)

Several gene therapies have shown early results in alleviating sickle cell disease symptoms, which includes sudden attacks of pain, debilitating fatigue, and emergency blood transfusions. Vertex Pharmaceuticals, working with CRISPR Therapeutics, has treated over 45 patients with sickle cell and beta thalassemia, with 22 of them seeing significant improvement, according to an *NPR* report. Bluebird Bio uses a viral vector to insert genes into blood cells, and has also seen success, although there have been some side effects that need to be evaluated. Still, sickle cell disease may be the first disease that is curable using genetic editing technologies.



“Supreme Court Has Voted to Overturn Abortion Rights, Draft Opinion Shows” by Josh Gerstein and Alexander Ward, *Politico*, May 2, 2022

The Supreme Court has voted to strike down the landmark *Roe v. Wade* decision, according to an initial draft majority opinion written by Justice Samuel Alito circulated inside the court and obtained by POLITICO. The draft opinion is a full-throated, unflinching repudiation of the 1973 decision which guaranteed federal constitutional protections of abortion rights and a subsequent 1992 decision—*Planned Parenthood v. Casey*—that largely maintained the right. (<https://tinyurl.com/ys7zvprb>)

Despite the media furor over the leaked document, there have been rumblings about the Supreme Court overturning *Roe* and *Casey* since December 2021. *Axios* reported on the oral arguments for the *Dobbs* case in “Supreme Court Appears Likely to Roll Back Abortion Rights.”³ One of the key points in the oral arguments was the “viability line” as the standard for when abortions are permitted under both court cases.

Someone associated with the U.S. Supreme Court leaked a draft majority opinion of the *Dobbs v. Jackson Women's Health Organization* case. The draft overturns *Roe* and *Casey*, which made the legalization of abortion protected by the federal constitution under the “right to privacy.” The draft, which was the precursor to the official opinion of the Court, published in June 2022, places the onus on the states and the legislature to determine the legality and boundaries of abortion.⁴

Even though in hindsight we know the leaked document turned out to be authentic, *Poynter* had a helpful article on the ethics of choosing to report a Supreme Court leak and a critique of *Politico's* lack of transparency on how they authenticated the documents.⁵

“US Overdose Deaths Hit Record 107,000 Last Year, CDC Says” by Mike Stobbe, *Associated Press*, May 11, 2022

More than 107,000 Americans died of drug overdoses last year, setting another tragic record in the nation's escalating overdose epidemic, the Centers for Disease Control and Prevention estimated Wednesday [May 11th]. The provisional 2021 total translates to roughly one U.S. overdose death every 5 minutes. It marked a 15% increase from the previous record, set the year before. The CDC reviews death certificates and then makes an estimate to account for delayed and incomplete reporting. (<https://tinyurl.com/mrxb-dv4w>)

Overdose deaths have been steadily increasing since the 1990s because of the availability of opioids. However, last year saw an increase in overdose deaths that were unevenly distributed across the U.S. and across socio-economic and racial groups. Native Americans and Black Americans saw the highest percentage increase in overdose deaths. Part of this was due to the stressors associated with the pandemic. However, another reason for an escalation of overdoses is due to pills, obtained illegally, that are tainted with fentanyl, a highly potent opioid.



“China's Treatment of Uyghurs Amounts to Genocide, U.K.-Based Panel Finds” by Sha Hua, *The Wall Street Journal*, December 9, 2021

An independent panel wrapped up its yearlong examination of China's treatment of Uyghurs and other ethnic minorities in Xinjiang, concluding that China's policies in the region amounted to a form of genocide. The Uyghur Tribunal, a U.K.-based panel of lawyers, academics and activists, said Thursday [December 9th] it found that the Chinese government, through policies including what it described as forced birth control and sterilizations, intends to partially destroy the predominantly Muslim Uyghur community and its way of life; and that Chinese President Xi Jinping and other senior officials bore “primary responsibility for acts in Xinjiang.” (<https://tinyurl.com/yhw9tjwc>)

“The Faces from China’s Uyghur Detention Camps” by John Sudworth, *BBC*, May 24, 2022

Thousands of photographs from the heart of China’s highly secretive system of mass incarceration in Xinjiang, as well as a shoot-to-kill policy for those who try to escape, are among a huge cache of data hacked from police computer servers in the region. (<https://tinyurl.com/43c2j2m6>)

An international tribunal comprised of lawyers, academics, activists, doctors, businessmen, and ex-diplomats determined that China has been engaging in an ethnic assimilation campaign that amounts to cultural genocide of the Uyghurs and other Turkic minorities living predominantly in China’s northwest province of Xinjiang (Xinjiang Uyghur Autonomous Region). The tribunal announced its findings in December, two months before the start of the Beijing Winter Olympics. The United States, Canada, the U.K., and several other countries said they would diplomatically boycott the Beijing Olympics due to human rights abuses.

Additionally, the United Nations International Labor Organization’s annual report found that China has continued to engage in forced labor and even physical and psychological torture of Uyghurs in Xinjiang. Those that had been detained are forced to work in inhumane conditions. Thousands of others have been forced to work in factories in other parts of China, separated from their families under a dubious labor transfer scheme called “Xinjiang Aid.”⁶

Then, in May, the *BBC* published photos of thousands of Uyghurs and other Turkic minorities who have been detained. These are from leaked documents of a police database from a province in Xinjiang, known as the “Xinjiang Files.” The files provide some of the starkest evidence of conditions in the detention camps. Additionally, *Axios* reported that a former detainee who is Christian, ethnically Kyrgyz, and trained in law, made it to the United States and will be a key witness for the International Criminal Court’s prosecution against China for committing crimes against humanity.



Notes

1. Nicole Wetsman, “FDA Warns That Some Prenatal Blood Tests Could Have False Results,” *The Verge*, April 19, 2022, <https://www.theverge.com/2022/4/19/23032608/fda-prenatal-blood-tests-false-results>.
2. Brandy Schillace, “The Capitalist Trap of Pig Organ Transplants,” *Wired*, January 27, 2022, <https://www.wired.com/story/capitalist-trap-pig-organ-transplants/>.
3. Oriana Gonzalez, “Supreme Court Appears Likely to Roll Back Abortion Rights,” *Axios*, December 1, 2021, <https://www.axios.com/2021/12/01/supreme-court-abortion-mississippi-viability>.
4. To read the finalized opinion, see *Dobbs v. Jackson Women’s Health Organization*, No. 19–1392 (U.S. Sup. Ct., June 24, 2022), https://www.supremecourt.gov/opinions/21pdf/19-1392_6j37.pdf.
5. Kelly McBride, “Politico’s Supreme Court Leak Leaves Some Linger Ethics Questions,” *Poynter*, May 2, 2022, <https://www.poynter.org/ethics-trust/2022/politico-supreme-court-leak-roe-v-wade-journalism-ethics/>.
6. Committee of Experts on the Application of Conventions and Recommendations, “Application of International Labour Standards 2022” (International Labour Organization, International Labour Conference 110th Session, 2022), Report III (Part A), 514–21, https://www.ilo.org/wcmsp5/groups/public/---ed_norm/---relconf/documents/meetingdocument/wcms_836653.pdf.