TOP BIOETHICS NEWS STORIES: SEPT 2017 – NOV 2017

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"US Overdose Deaths from Fentanyl and Synthetic Opioids Doubled in 2016" by Edward Helmore, *The Guardian*, September 3, 2017

> The number of drug overdose deaths in the US increased by 21% last year, according to new statistics—with synthetic-opioid fatalities more than doubling in number. The National Center for Health Statistics, a division of the Centers for Disease Control and Prevention, (CDC) estimates that drug overdoses killed 64,070 people in the US last year, a rise of 21% over the 52,898 drug overdose deaths recorded in 2015. (https://tinyurl.com/ya5g8orl)

While the number of people who died from heart disease and cancer has decreased, the number of people who have died from drug overdose has increased substantially. Fentanyl, in particular, has been found in many of the victims of overdoses. As a result of the increasing number of deaths from opioids, President Trump declared a public health emergency in late October 2017.

"New Gene-Therapy Treatments Will Carry Whopping Price Tags" by Gina Kolata, *New York Times*, September 11, 2017

> With gene therapy, scientists seek to treat or prevent disease by modifying cellular DNA. Many such treatments are in the wings: There are 34 in the final stages of testing necessary for F.D.A. approval, and another 470 in initial clinical trials, according to the Alliance for Regenerative Medicine, an advocacy group. The therapies are aimed at extremely rare diseases with few patients; most are meant to cure with a single injection or procedure. But the costs . . . are expected to be astronomical, alarming medical researchers and economists. (https://tinyurl.com/y8oh7meb)

"$1 Million Price Tag in Spotlight as Gene Therapy Becomes Reality" by Ben Hirschler, *Reuters*, November 16, 2017

> Battle lines are being drawn as the first gene therapy for an inherited condition nears the U.S. market, offering hope for people with a rare form of blindness and creating a cost dilemma for healthcare providers. Spark Therapeutics, whose Luxturna treatment has been recommended for U.S. approval, told investors last week there was a case for valuing it at more than $1 million per patient, although it has yet to set an actual price. (https://tinyurl.com/ycbpa4zn)

As gene therapies come to market, they are carrying a price tag in the hundreds of thousands of dollars, with one therapy priced at $1 million. Drug companies say this is necessary to recoup the costs for R&D for drugs that will only go to a small population as a one-time fix (https://tinyurl.com/yadmn2va). These therapies are prohibitively expensive for many of the people who need them.

"DNA Surgery on Embryos Removes Disease" by James Gallagher, *BBC*, September 28, 2017

> Precise "chemical surgery" has been performed on human embryos to remove disease in a world first, Chinese researchers have told the BBC. The team at Sun Yat-sen University used a technique called base editing to correct a single error out of the three billion "letters" of our genetic code. They altered lab-made embryos to remove the disease beta-thalassemia. The embryos were not implanted. The team says the approach may one day treat a range of inherited diseases. (https://tinyurl.com/y6wk7ysh)

Chinese researchers made a human embryo via cloning that was genetically modified with the mutation that causes beta-thalassemia. They then demonstrated how using a version of CRISPR-Cas9 gene editing technique was able to change the one base letter that causes the disease. This raised several ethical questions and has spurred the U.S. and UK to consider what kinds of experiments they would allow (https://tinyurl.com/y886bd6f and https://tinyurl.com/ybaa9gpz). Following on the 2015 news of human embryo gene editing in China and the reports in July 2017 of a U.S. team editing genes of human embryos in Oregon, CNN quoted genetics professor David Griffin as saying, "For many years we have been saying that direct gene editing in embryos is some way in to the future. Now the future is here and there is much to consider" (https://tinyurl.com/yav766v8).

"Puerto Rico's Slow-Motion Disaster" by Eric Niler, *Wired*, September 29, 2017

> Hurricane Maria left a ruined island and 16 Puerto Rico residents dead. But public health experts worry that figure could climb higher in the coming weeks, as many on the island fail to get medicines or treatment they need for chronic diseases. Roads are blocked, supplies are stuck at the ports, and only 11 of Puerto Rico's 69 hospitals are open. Doctors at one children's hospital were forced to discharge 40 patients this week when their generator ran out of diesel fuel. (https://tinyurl.com/yaj57kfr)

Hurricanes Harvey, Irma, and Maria wreaked havoc on the U.S. Gulf Coast and Caribbean Islands. Puerto Rico, in particular, has faced a public health crisis after Hurricane Maria tore through the island. As of this writing, only half of the island has power. Many people have died from treatable conditions in the aftermath of these storms because the medical infrastructure has not been restored.

"More than 2,000 Canadians Have Died with Medical Assistance Since Legalization" by Kathleen Harris, *CBC News*, October 6, 2017.

> More than 2,000 Canadians have ended their lives legally with the help of a doctor, and most of them were suffering from terminal cancer. According to the latest report from Health Canada, there were 1,982 medically assisted deaths in the one-year period after it became legal in June 2016. (https://tinyurl.com/yc3t3z42)

"'Any Taboo Has Gone': Netherlands Sees Rise in Demand for Euthanasia" by Daniel Boffey, *The Guardian*, November 9, 2017.

> The number of people euthanised in the Netherlands this year is set to exceed 7,000—a 67% rise from five years ago—in what has been described by the director of the country's only specialist clinic as the end of "a taboo" on killing patients who want to die. (https://tinyurl.com/y9k8a3h4)

"Australian State Legalises Assisted Dying 20 Years after Country Repeals World's First Mercy-Killing Law" by Rod McGuirk, *Independent*, November 29, 2017

> An Australian state parliament has legalized voluntary euthanasia 20 years after the country repealed the world's first mercy-killing law for the terminally ill. The final vote in the Victorian parliament means that doctor-assisted suicide will be allowed in Australia's second-most populous state from mid-2019. (https://tinyurl.com/yaznfk94)

Physician-assisted suicide was legalized in Canada in June 2016, with 803 people dying from physician-assisted suicide in the first six months (with only 5 cases being self-administered). Over the next six months (January to June 2017), another 1,179 people died from assisted-suicide. Most had terminal cancer. In November, assisted-suicide was legalized in Victoria, Australia. And in The Netherlands, demand for euthanasia has grown so much that organizations are looking for more doctors and nurses to help meet the demand for assisted suicide and, in some cases, even to provide the direct administration of the lethal drugs.

"Eugenics 2.0: We're at the Dawn of Choosing Embryos by Health, Height, and More" by Antonio Regalado, *MIT Technology Review*, November 1, 2017

> IVF clinics already test the DNA of embryos to spot rare diseases, like cystic fibrosis, caused by defects in a single gene. But these "preimplantation" tests are poised for a dramatic leap forward as it becomes possible to peer more deeply at an embryo's genome and create broad statistical forecasts about the person it would become. The advance is occurring, say scientists, thanks to a growing flood of genetic data collected from large population studies. (https://tinyurl.com/y84glm7p)

The use of massive amounts of data to make statistical predictions is being studied as a means to make predictions about IVF embryos. For example, height is the easiest to predict because it is largely genetic and is recorded in databases. Researchers hope that large amounts of genomic data could make predicting (in the statistical sense) late-life diseases and certain traits possible. One of the major firms in preimplantation genetic testing is keenly interested in identifying not only disease, but also IQ.

"A Dying Boy Gets a New, Gene-Corrected Skin" by Ed Yong, *The Atlantic*, November 8, 2017

> [Hassan was born with a genetic disorder that causes blistering and tearing of the skin.] In August, De Luca and Pelligrini got the green light to try their technique. In September, they collected a square inch of skin from Hassan's groin—one of the few parts of his body with intact skin. They isolated stem cells, genetically modified them, and created their gene-corrected skin grafts. In October and November, they transplanted these onto Hassan, replacing around 80 percent of his old skin. It worked. In February 2016, Hassan was discharged from the hospital. In March, he was back in school. He needs no ointments. His skin is strong. It doesn't even itch. (https://tinyurl.com/y9xjeov6)

"A Human Has Been Injected with Gene-Editing Tools to Cure his Disabling Disease " by Jocelyn Kaiser, *Science*, November 15, 2017

> For the first time, researchers have infused a person's blood with gene-editing tools, aiming to treat his severe inherited disease . . . . The 44-year-old patient has a rare metabolic disorder called Hunter syndrome. But how big is the advance—and what does it mean for using hot new technologies such as CRISPR to help people with other genetic diseases? (https://tinyurl.com/yc3rbh4t)

An adult stem cell therapy that made headlines this fall was for a boy with epidermolysis bullosa (EB), a disease resulting in fragile skin that blisters and tears. Researchers took the boy's stem cells from a portion of skin, genetically modified the genes that cause EB, and grew new skin with the edited cells. They then did a skin graft. So far there have been no negative effects from the genetic modification. The boy is able to lead a relatively normal life and has not had blisters.

In other news, 44-year-old Brian Madeux became the first person to receive a gene editing treatment that is intended to repair the genes that cause Hunter syndrome inside his own body. As of early 2018, the treatment appears not to have caused any major concerns, and a second patient with Hunter syndrome has now been treated (https://tinyurl.com/y8yj86cd). These are only a few of the growing list of diseases gene therapy is showing promise for (https://tinyurl.com/y792e8qy).

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