

# TOP BIOETHICS NEWS STORIES: SEPTEMBER 2018–NOVEMBER 2018

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**“Infanticide in Kenya: ‘I Was Told to Kill My Disabled Boy’”** by Anne Soy, *BBC*, September 27, 2018

Ms Njoki and Ms Kipchumba are not alone. A new study in Kenya has found that 45% of mothers interviewed by a leading charity faced pressure to kill their babies born with disabilities. The survey found that the situation was worse in rural areas—where the figure could be as high as two in every three mothers. (<https://tinyurl.com/y9gfms98>)

In Kenya, women are coerced into killing their disabled babies. Some of this is due to cultural beliefs that a disabled child is a punishment from God for a woman cheating on her husband or that a mother is “cursed” or “bewitched.” To some, killing the child is the most loving thing to do. Disability Rights International interviewed several women who decided to raise their disabled children despite societal pressure to kill them. These women work together to support children with disabilities. These situations in Kenya are just one example of the stigma many people with disabilities face around the world.

**“Mosquitoes Genetically Modified to Crash Species That Spreads Malaria”** by Rob Stein, *NPR*, September 24, 2018

For the first time, scientists have demonstrated that a controversial new kind of genetic engineering can rapidly spread a self-destructive genetic mod-

ification through a complex species. The scientists used the revolutionary gene-editing tool known as CRISPR to engineer mosquitoes with a “gene drive,” which rapidly transmitted a sterilizing mutation through other members of the mosquito’s species. (<https://tinyurl.com/ybvs8erk>)

Malaria kills almost half a million people worldwide every year. It is a parasite that is carried in the *Anopheles gambiae* mosquito species. A controversial experiment genetically modified males in the species so that they are sterile. When let into a contained environment, the mosquitoes eventually died out. If successful, this will help curb one of the deadliest human diseases in history.

**“Thousands of Foster Children May Be Getting Psychiatric Drugs Without Safeguards, Watchdog Agency Says”** by Ricardo Alonso-Zaldivar, *STAT News*, September 17, 2018

A report released Monday by the Health and Human Services inspector general’s office found that about 1 in 3 foster kids from a sample of states were prescribed psychiatric drugs without treatment plans or follow-up, standard steps in sound medical care. Kids getting mood-altering drugs they don’t need is only part of the problem. Investigators also said children who need medication to help them function at school or get along in social settings

may be going untreated. (<https://tinyurl.com/yxejeow>)

There are many ethical concerns with giving children powerful psychiatric drugs. Often these drugs require professional monitoring and dose adjustment. However, many foster children receive drugs that they may or may not need while follow-up care is often lacking. Foster children have a higher incidence of mental health and behavioral problems more than non-fostered children likely due to past traumatic experiences. They are reportedly not getting the mental health care and support that they need, which is part of a larger trend in the US to over-medicate and under-treat mental health problems.

**“CRISPR’s Epic Patent Fight Changed the Course of Biology”** by Megan Molteni, *Wired*, September 11, 2018

After three bitter years and tens of millions of dollars in legal fees, the epic battle over who owns one of the most common methods for editing the DNA in any living thing is finally drawing to a close. On Monday, the US Court of Appeals for the Federal Circuit issued a decisive ruling on the rights to Crispr-Cas9 gene editing—awarding crucial intellectual property spoils to scientists at the Broad Institute of Cambridge, Massachusetts. (<https://tinyurl.com/y3oa8fj6>)

The patent battle between the University of California Berkeley and the Broad

Institute of Cambridge, Massachusetts, finally came to a close as the courts ruled in favor of the latter. However, the victory was somewhat anti-climactic. While the three-year legal battle progressed, scientists have been working on innovative ways to improve the CRISPR-Cas9 system. In particular, they have looked at enzymes other than Cas9 to make more precise edits.

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**“Cases of Mysterious Paralyzing Condition Continues to Increase, CDC Says”** by Rob Stein, *NPR*, November 13, 2018

The number of children being stricken by a mysterious paralyzing condition continues to increase, federal officials say. At least 252 cases of acute flaccid myelitis, or AFM, have been reported to the Centers for Disease Control and Prevention so far this year from 27 states, including 90 that have been confirmed through Nov. 9, the CDC reported Tuesday. Most of the cases have occurred among children between the ages of 2 and 8. (<https://tinyurl.com/ybb7s5l8>)

In the fall of 2014 one hundred twenty children suddenly experienced paralysis after having cold-like symptoms. There had been reports of cases in 2012, but 2014 showed a marked increase in acute flaccid myelitis (AFM). In the fall of 2016, one hundred fifty-three children were confirmed to have AFM. Then, in the fall of 2018, two hundred thirty-six children were confirmed to have it. While evidence pointed to an enterovirus strain, it will not be until a year later, in October of 2019, that scientists confirm the presence of enterovirus D68 and A71 antibodies in these children’s spinal fluid.

**“Chinese Researcher Claims Birth of First Gene-Edited Babies—Twin Girls”** by Marilyn Marchione, *STAT News*, November 25, 2018

A Chinese researcher claims that he helped make the world’s first genetically edited babies—twin girls born this month whose DNA he said he altered with a powerful new tool capable of rewriting the very blueprint of life. (<https://tinyurl.com/y4yzbfnd>)

**“He Took a Crash Course in Bioethics. Then He Created CRISPR Babies”** by Sharon Begley, *STAT News*, November 27, 2018

For someone who has caused a worldwide uproar over what many fellow scientists consider an ethical outrage, He Jiankui of China spent a remarkable amount of time discussing his work—which he claims led to the births of the first babies whose genomes had been edited when they were IVF embryos—with bioethicists, policy experts, and social scientists. Two of them are father and son: Dr. William Hurlbut of Stanford University, a member of the U.S. President’s Council on Bioethics in the early 2000s, and J. Benjamin Hurlbut of Arizona State University, a biomedical historian. (<https://tinyurl.com/y2e8n2w4>)

*(Editor’s Note: William Hurlbut is a Distinguished Fellow with The Center for Bioethics & Human Dignity’s Academy of Fellows, and J. Benjamin Hurlbut has been a plenary speaker at CBHD’s annual summer conference. Both disagreed with He Jiankui’s actions.)*

The biggest bioethics story from Fall 2018 was the announcement that He Jiankui from the University of Science and Technology in Shenzhen had im-

planted two genetically modified embryos that were gestated to full term and born in August. He further announced that another pregnancy is underway. There was an international outcry over the experiment because the employed gene editing technology, CRISPR-Cas9, is still being investigated for safe clinical use. Additionally, the embryos He modified were healthy, meaning there was no therapeutic reason to modify them. Furthermore, there was controversy over whether He obtained proper approval from the university ethics committee and informed consent from the parents.

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**“Ebola Outbreak in DR Congo Now Second Worst in History,”** *BBC*, November 30, 2018

The UN’s global health body says the Ebola outbreak in the east of the Democratic Republic of Congo is now the second-biggest ever recorded. A total of 426 cases of the virus have now been reported in and around the town of Beni, taking the outbreak past that recorded in Uganda in 2000. Beni is in the middle of a conflict zone and operations have been affected by rebel attacks. (<https://tinyurl.com/y2xt9yue>)

Containing the Ebola outbreak in the DRC has met some challenges because of an inherent lack of trust toward foreign medical workers administering vaccines and therapies. Rebel raids and in-fighting has even worsened the situation. The outbreak, which had over 400 cases in the fall of 2018, will eventually report over 3,000 cases in 2019.

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