

## TOP BIOETHICS NEWS STORIES: DECEMBER 2015 – FEBRUARY 2016

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**“In Syria, Health Care Workers Are the Heroes—and the Targets”** by Maanvi Singh, *NPR*, December 1, 2015

Since the conflict in Syria began in 2011, nearly 700 medical workers have been killed and more than 300 facilities have been hit with missile strikes and bombs, according to the advocacy group Physicians for Human Rights. In an article last month in the *New England Journal of Medicine*, American doctors said that their counterparts in Syria need help: The disruption of health services has become a weapon of war that the Syrian government is using against those opposed to President Bashar Assad. (<http://tinyurl.com/ptvv926>)

In war-torn Syria, hundreds of doctors are being killed, medical facilities are being targeted by air strikes, and supplies are dwindling. More than half of the Syrian population is displaced, causing a refugee crisis throughout Europe. Those that have remained in the war-zone are in need of the medical facilities available, but many doctors are fleeing for their lives. Targeting medical facilities and doctors goes against the rules of engagement as outlined in the Geneva Conventions.

**“India Scales Back ‘Rent-a-Womb’ Services”** by Shashank Bengali, *Los Angeles Times*, January 25, 2016

Chasing dreams of financial independence, thousands of poor Indian women have found work as surrogate mothers, helping to turn this country into a favored destination for foreign couples who can’t become pregnant on their

own. Now India’s government is taking the first significant steps to rein in commercial surrogacy, citing fears that the women are being exploited by a mushrooming industry that pays them a fraction of what surrogates earn in the West. (<http://tinyurl.com/h6gqcfp>)

**“Surrogate Carrying Triplets Sues to Stop Forced Abortion”** by Carl Campanile, *New York Post*, January 4, 2016

A surrogate mom who refuses to abort one of the triplets she’s carrying because the father only wants two of the kids filed a lawsuit Monday claiming that California’s surrogacy law is unconstitutional. (<http://tinyurl.com/jarul5l>)

Two stories this quarter have shed light on the darker side of gestational surrogacy. On the international front, India, a go-to hot spot for foreigners looking for a gestational surrogate, has tightened its rules on surrogacy for fear that poor Indian women are being exploited. In the U.S., Melissa Cook made headlines when she refused to abort one of the triplets that she was carrying for a single father. She had offered to adopt the unwanted child, but the father refused, saying he wanted her to abort it and that she was in violation of her contract. Later reports revealed that the father, at first, wanted to abort all three babies because he could not afford the hospital fees.

**“Bitter Fight over CRISPR Patent Heats Up”** by Heidi Ledford, *Nature*, January 12, 2016

A versatile technique for editing genomes has been called the biggest

technology advance since the polymerase chain reaction (PCR), and the US Patent and Trademark Office (USPTO) is set to determine who will reap the rewards. On 11 January, the USPTO granted a request to review a key patent awarded for the technique, known as CRISPR–Cas9. The outcome of the ensuing proceedings, called a patent interference, could be worth millions to the research institutions that are at war over the relevant patents. It might also influence who is allowed to use the technology—and under what terms. (<http://tinyurl.com/zt6wjpk>)

Since the initial publications of the CRISPR/Cas9 system in 2012, hundreds of papers have reported experiments using the robust gene-editing technology. Its ability to cut-and-paste gene sequences in multiple locations means that the patent could be worth millions of dollars to the institution that filed the patent. However, there is an ongoing legal dispute over who should be the proper holder of the patent rights between Jennifer Doudna of the University of California, Berkeley and Emmanuelle Charpentier, now at the Max Planck Institute for Infection Biology on the one hand or Feng Zhang at the Broad Institute and Massachusetts Institute of Technology. As of this writing, the dispute remains unresolved.

**“UK Scientists Gain License to Edit Genes in Human Embryos”** by Ewen Callaway, *Nature*, February 1, 2016

Scientists in London have been granted permission to edit the genomes of human embryos for research,

UK fertility regulators announced. The 1 February approval by the UK Human Fertilisation and Embryology Authority (HFEA) represents the world's first endorsement of such research by a national regulatory authority. (<http://tinyurl.com/hl2box2>)

HFEA approved the use of the gene editing technology CRISPR/Cas9 in healthy human embryos for research purposes. As part of the stipulations for approval, the embryos must be destroyed after seven days. Researchers hope to use this technique to understand early development and infertility. This comes after a U.S. summit determined that it would be “irresponsible” at this time to alter the genomes of human embryos or gametes to produce a baby.

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**“For Boys Only? Panel Endorses Mitochondrial Therapy, but Says Start with Male Embryos”** by Gretchen Vogel, *Science*, February 3, 2016

An experimental assisted reproduction technique that could allow some families to avoid having children with certain types of heritable disease should be allowed to go forward in the United States, provided it proceeds slowly and cautiously. That is the conclusion of a report released today [February 3<sup>rd</sup>] from a panel organized by the U.S. National Academies of Sciences, Engineering, and Medicine (NAS), which assesses the ethics questions surrounding the controversial technique called mitochondrial DNA replacement therapy. (<http://tinyurl.com/gn8hrb7>)

A U.S. ethics panel says that mitochondrial replacement therapy—also referred to as mitochondrial donation or transfer and popularly dubbed “three-parent embryos,”—should be approved by the Food and Drug Administration for women who do not want to pass on the risk of mitochondrial disease to their children.

The research cannot occur during this fiscal year, however, due to the 2016 congressional bill banning the use of government funds for experiments that genetically alter human embryos. Interestingly, the panel recommends using the technique on male embryos only, so as to avoid the potential of hereditary concerns commonly raised for germline gene interventions. Additional concerns have been raised by some that the shift away from technical terms such as ‘maternal spindle transfer’ or ‘pronuclear transfer’ in favor of terms such as ‘mitochondrial donation or transfer’ minimizes the risks and significance of the procedures.

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**“200 Million Girls and Women Living with FGM: UNICEF”** *Medical Xpress*, February 5, 2016

At least 200 million girls and women worldwide have been subjected to female genital mutilation with half of those living in Egypt, Ethiopia and Indonesia, according to the UN children's agency. Somalia, Guinea and Djibouti continue to show the highest prevalence of FGM globally, but the overall rate in some 30 countries has dropped, said a UNICEF report released ahead of International Day of Zero Tolerance for FGM, on Saturday. (<http://tinyurl.com/jfn8upl>)

**“Female Genital ‘Nicks’ Should Be Legal: Gynecologists”** by Emma Batha, *Reuters*, February 22, 2016

Countries that have banned female genital mutilation (FGM) should allow less invasive practices such as small surgical nicks to girls' genitalia as a compromise, two American gynecologists said on Monday. (<http://tinyurl.com/zortpd5>)

A controversial proposal by two American gynecologists writing in the *Journal of Medical Ethics* has made headlines for suggesting a compromise to female genital mutilation. FGM is recognized by many as a violation of human dignity, and the UN hopes to complete-

ly eliminate the practice by 2030. The authors of the article suggest allowing for small nicks on the clitoris as a compromise. They also suggest changing the name to “female genital alteration” to avoid “demonizing important cultural practices.”

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**“Assisted Suicide Study Questions its Use for Mentally Ill”** by Benedict Carey, *New York Times*, February 10, 2016

A new study of doctor-assisted death for people with mental disorders raises questions about the practice, finding that in more than half of approved cases, people declined treatment that could have helped, and that many cited loneliness as an important reason for wanting to die. The study of cases in the Netherlands should raise concerns for other countries debating where to draw the line when it comes to people's right to die, experts said. (<http://tinyurl.com/z7r6yo2>)

A study of assisted suicide cases in The Netherlands showed that, of the people who elected to have physician-assisted suicide for mental health reasons, more than half declined treatment that could have helped. Many patients received approval from doctors that they had only seen once, sometimes going to a mobile “end-of-life clinic” funded by a local euthanasia advocacy group. Notably, the majority of the mental health cases were women, and loneliness was a common theme. This has implications for places such as Canada, where physician-assisted suicide was recently legalized, and the various U.S. states where physician-assisted suicide is either legal or is being debated in the state legislature.

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