news update

TOP BIOETHICS STORIES: JUNE - AUGUST 2014

BY HEATHER ZEIGER, MS, MA RESEARCH ANALYST

"Air Thick with Self-Congratulation as Quebec Votes to Legalize Euthanasia" by Graeme Hamilton, *National Post*, June 5, 2014

As Quebec's National Assembly voted Thursday to become the first North American jurisdiction to legalize euthanasia, the air was thick with self-congratulation. 'I want to congratulate ourselves as parliamentarians,' PQ MNA Carole Poirier said before the vote. 'Quebec is a beautiful society, and again today Quebec has just shown that we are really, really a different society.' (http://tinyurl.com/qhpcqbt)

"Three European Courts Grapple with End-of-Life Dilemmas" by Tom Henehan, *Reuters*, June 25, 2014

Three European courts stepped carefully around delicate end-of-life issues on Wednesday, with one rejecting assisted suicide, another delaying it and a third acquitting a doctor from charges he murdered dying patients. The varied rulings by Britain's Supreme Court, the European Court of Human Rights and a regional French court reflected the difficulty of drawing a clear legal line between aiding terminal patients to die in peace and committing murder. (http://tinyurl.com/qd6bnbw)

Physician-assisted suicide has been heavily covered in the media this past summer as several countries voted on laws permitting some form of assisted suicide. In response to Great Britain's discussion on whether to legalize physician-assisted suicide, the British Medical Journal surprisingly called for legalizing assisted suicide, citing that respect for autonomy rather than the ideas espoused in the Hippocratic Oath are now more important in medical ethics. Additionally, a paper in the journal Law, Ethics, and Medicine provided statistics on suicide tourism to Switzerland, which has been on the

rise over the past ten years. Tourists come from countries that do not allow physician-assisted suicide to take advantage of Switzerland's hazy laws on the issue.

"Paralyzed Man in Robotic Body Suit Will Kick Off World Cup" by Noah Rayman, *Time*, June 12, 2014

A paraplegic man in a state of the art brain-controlled body suit will make the first kick of the World Cup on Thursday in front of 1 billion people. Miguel Nicolelis, a Brazilian neuroscientist at Duke University, led a team of 156 researchers to create an exoskeleton that could enable people who are paralyzed to walk, and the technology will be displayed in action during the World Cup's opening ceremonies ahead of the first match, Brazil vs. Croatia, in Sao Paulo. (http://tinyurl.com/n96hqpg)

Several networks were criticized for not covering the traditional first kick of the World Cup in favor of more entertaining acts. However, that first kick is of interest to bioethicists because it was performed by Juliano Pinto, a 29-year-old man who is paralyzed from the waist down. Juliano was wearing a robotic exoskeleton that is part of research being conducted for the Walk Again Project. Other World Cup bioethics news included Angel Di Maria, winger for Argentina, undergoing stem cell treatment for a torn right hamstring.

"Supreme Court Rejects Contraceptive Mandate for Some Corporations" by Adam Liptak, *The New York Times*, June 30, 2014

The Supreme Court ruled on Monday that requiring family-owned corporations to pay for insurance coverage for contraception under the Affordable Care Act violated a federal law protecting religious freedom. It was, the dissent said, "a decision of startling breadth." The 5-to-4 ruling,

which applied to two companies owned by Christian families, opened the door to challenges from other corporations over laws that they claim violate their religious liberty. (http://tinyurl.com/n2ytrau)

A preventive care regulation developed as part of the implementation of the Affordable Care Act specifies that employers cover contraceptives in their health insurance, including some contraceptives that may act as an abortifacient. The Supreme Court ruled in favor of tightly held corporations like Hobby Lobby and Conestoga Wood that have a religious objection to such coverage. The Obama administration has since revised an opt-out clause to the contraceptive mandate that would allow tightly held corporations such as Hobby Lobby to exclude coverage of certain contraceptives on the ground of religious objections. In August, the administration drafted a new policy allowing employees of such companies to receive coverage for contraceptives directly through the insurance company.

"Papers on 'Stress-Induced' Stem Cells Are Retracted" by David Cyranoski, Nature, July 2, 2014

Nature today retracted two controversial papers on stem cells that it published in January. The retractions — agreed to by all of the co-authors — come at the end of a whirlwind five months during which various errors were spotted in the papers, attempts to replicate the experiments failed, the lead author was found guilty of misconduct, and the centre where she is employed was threatened with dismantlement. The retraction notice includes a handful of problems with the papers that had not been previously considered by institutional investigation teams. (http://tinyurl. com/ngwdflz)

The STAP stem cell saga, which began

news update

with the publication of two papers in January, concluded in July with the retraction of those papers after lead author Haruko Obokata and co-author Charles Vacanti finally consented to retraction. Investigators found several problems with the papers, including doctored and duplicated images. Obokata was charged with misconduct by her institution, but still stands by her work. Vacanti has since stepped down as chair of the anesthesiology department at Brigham and Women's Hospital. In August, one of the paper co-authors, Yoshiki Sasai, committed suicide. In his suicide note, he tragically blamed the media attention from the retracted papers for his distress.

"Vials of Smallpox Virus Found in Unapproved Maryland Lab" by Sydney Lupkin, *ABC News*, July 8, 2014

Vials of the virus that causes small-pox were found in a National Institutes of Health research building that was unequipped and unapproved to handle the deadly pathogen, according to the Centers for Disease Control and Prevention. Because it's so infectious, the smallpox virus is considered a bioterrorism threat and is only permitted in two labs in the world: One at the CDC's Atlanta headquarters and another at the VECTOR Institute in Russia. (http://tinyurl.com/n77vnxn)

Vials containing the smallpox virus were found in a cold storage room in an unapproved NIH laboratory. This sparked an investigation into government labs. Investigators eventually found six more vials of dangerous pathogens that were improperly stored and reported in other NIH and FDA labs. Furthermore, investigations into the CDC's bioterrorism labs found improper storage and handling of anthrax, leading to a government investigation and the eventual resignation of the head of the CDC's Bioterrorism Rapid Response and Advanced Technology lab.

"Europe Moves to Outlaw Organ

Trafficking Worldwide" by Matthew Robertson, *Epoch Times*, July 17, 2014

An official European representative body has promulgated a new convention outlawing the trafficking in human organs, calling on all countries to become signatories to it and criminalize the practice and punish offenders. The convention, called the 'Council of Europe Convention against Trafficking in Human Organs' was adopted by the Council of Europe's Committee of Ministers on July 9. The Council of Europe is composed of 47 member states; it does not make binding laws, but provides policy guidelines and promotes good governance. (http:// tinyurl.com/md3ots3)

While it is difficult to determine how many illegal organ trafficking rings there are, news headlines this summer have reported illegal organ trafficking in Nepal, India, Kosovo, and China. China, especially, is a difficult dilemma because it is the most populous country in the world, and therefore, in need of organs for donation, but has few rules governing the practice. For years there have been several reports of Chinese authorities obtaining organs from prisoners and favoring rich foreigners in distributing those organs.

"More than 100 Genetic Locations Found to Be Linked to Schizophrenia" by Sara Reardon, *Scientific American*, July 22, 2014

Researchers seeking to unpick the complex genetic basis of mental disorders such as schizophrenia have taken a huge step towards their goal. A paper published in *Nature* this week ties 108 genetic locations to schizophrenia — most for the first time. The encouraging results come on the same day as a US\$650-million donation to expand research into psychiatric conditions. (http://tinyurl.com/mpwoe3z)

A report on the genetic markers for schizophrenia and another report on the genetic markers for autism were produced by the Psychiatric Genomics Consortium. They examined large genetic samples to find patterns in people with a psychiatric disease to compare with those who do not have the disease. For the schizophrenia study, samples were pooled from 150,000 people, in which 36,989 were diagnosed with this psychiatric condition. Researchers found 108 genetic locations that seem to coincide with people with schizophrenia. Bioethics issues from this research include among other considerations privacy issues regarding genetic data along with potential discrimination or eugenic practices from finding genetic markers for a mental illness.

"IVF Technique that Tests Embryos for Genetic Disorders Has First Success" by Ian Sample, *The Guardian*, July 27, 2014

Doctors in London have reported the first pregnancy in Europe from a new IVF procedure that checks embryos for genetic disorders before they are implanted. The technique allows doctors to select embryos that are free of dangerous mutations carried by one or both parents even if the precise nature of the genetic defect is unknown. (http://tinyurl.com/ovuobd5)

In both the U.K. and the U.S., embryos created by IVF were successfully screened using genetic sequencing techniques. In the U.K. case, the doctors looked at a gene from one of the parents that codes for a type of muscular dystrophy that they did not want to pass on to their child. The doctors were able to remove a cell from an early embryo and screen it before implantation. Similarly, doctors in the U.S. sequenced the genome of several early embryos before implantation in an effort to select the "healthiest" looking embryo, ensuring a higher chance of a successful pregnancy. This technology has the potential to be used for eugenic purposes and has already been used to select embryos that do not have chromosomal abnormalities, such as Down syndrome.