

TOP BIOETHICS NEWS STORIES: SEPTEMBER – NOVEMBER 2013

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“NIH Program Explores the Use of Genomic Sequencing in Newborn Healthcare” *National Institutes of Health*, September 4, 2013

Can sequencing of newborns’ genomes provide useful medical information beyond what current newborn screening already provides? Pilot projects to examine this important question are being funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the National Human Genome Research Institute (NHGRI), both parts of the National Institutes of Health. (<http://tinyurl.com/mwnc6yk>)

In the U.S., newborns are typically screened for certain diseases such as phenylketonuria or cystic fibrosis. Genetic sequencing is only used to confirm screening results. The NIH is now considering using genetic sequencing as standard procedure for newborn care. However, with genetic sequencing come questions of privacy, consent, and the potential for genetic discrimination.

“Golden Rice Not So Golden for Tufts” by Martin Enserink, *Science Insider*, September 18, 2013

A study in which Chinese children were fed a small amount of genetically modified rice violated university and U.S. federal rules on human research, according to a statement issued yesterday [September 17] by Tufts University in Boston, whose scientists led the study. Tufts has barred the principal investigator, Guangwen Tang, from doing human research for 2 years and will require her to undergo training in research on human subjects. (<http://tinyurl.com/m3yzv72>)

After a year-long investigation, Tufts University and outside investigators

released a report on a controversial trial involving children from China and “golden rice.” Golden rice is genetically modified to contain beta carotene, which increases vitamin A in the body. The study was to see if golden rice would counter vitamin A deficiencies in Chinese children. While the study goals were noble, the way that Tang and her team obtained consent from those involved in the study was deemed inappropriate.

“Stem Cells Made with Near-Perfect Efficiency” by Monya Baker, *Nature*, September 18, 2013

Researchers have for the first time converted cultured skin cells into stem cells with near-perfect efficiency. By removing a single protein, called Mbd3, a team at the Weizmann Institute of Science in Rehovot, Israel, was able to increase the conversion rate to almost 100% — ten times that normally achieved. The discovery could clear the way for scientists to produce large volumes of stem cells on demand, hastening the development of new treatments. (<http://tinyurl.com/m5vo7s3>)

Shinya Yamanaka and John Gurdon shared the Nobel Prize in Physiology and Medicine for determining a process that converts a person’s skin cells into induced pluripotent stem cells. However, this process was fairly inefficient. The results yielded a small percentage of induced pluripotent stem cells mixed in with skin cells. Scientists found that if they turn off a protein that effectively tells cells to stop being pluripotent, they can convert skin cells to induced pluripotent stem cells with approximately 100% efficiency.

“Health Exchanges Open for Business—with Glitches” by Christopher

Weaver, Timothy W. Martin, and Louise Radnofsky, *The Wall Street Journal*, October 1, 2013

The health-insurance marketplaces at the center of President Barack Obama’s health law saw a surge of consumer interest Tuesday that surprised even many of the law’s backers. But the debut proved patchy, with few applicants actually able to buy coverage on clogged websites that were bedeviled with technological problems. (<http://tinyurl.com/KNPKPJG>)

Among the top bioethics news items for this quarter, the highest profile news item was the launch of the government’s healthcare exchange web site. Its anticlimactic launch continues to make headlines due to glitches, controversy, and misunderstandings over who is eligible for subsidized coverage. Currently, the Obama administration is considering a bill that will allow people to stay on their current insurance plan for another year.

“Silk Road Closure Will Be ‘Devastating’ for Australians Trying to Buy Nembutal” by Australian Associated Press, *The Guardian*, October 4, 2013.

The closure by US authorities of the black market Silk Road website will have a devastating effect on some elderly Australians, says the euthanasia advocate Dr Philip Nitschke. They were using the site to source reliable quantities of the “premier” end-of-life drug Nembutal, Nitschke, director of Exit International, said on Friday. (<http://tinyurl.com/MPZKZ85>)

The Silk Road made headlines for eluding the authorities and for re-launching after the owner was arrested. The Silk Road was a repository for black market drugs, hit men, and other nefarious items. Importantly, this was where many people wanting to end their life would

obtain black market drugs such as Nembutal with complete anonymity.

“IVF Babies ‘Are a Third More Likely to Develop Childhood Cancer’” by Nick McDermott, *The Daily Mail*, October 4, 2013

Scientists said those born after fertility treatments were 33 per cent more likely to have childhood cancer. They were 65 per cent more likely to develop leukaemia and 88 per cent more likely to develop cancers of the brain and central nervous system. The study suggests fertility treatment may change the way certain genes function when they are passed from parent to child in a process known as ‘genomic imprinting’. These faults in genes are linked to childhood cancers, the Danish researchers said. (<http://tinyurl.com/nkbnep4>)

“No Excess Cancer in IVF Babies” by Chris Kaiser, *Med Page Today*, November 6, 2013

Overall, assisted reproduction was not associated with an increased risk of leukemia, neuroblastoma, retinoblastoma, central nervous system tumors, or renal or germ-cell tumors, according to the study published online Nov. 6 in the *New England Journal of Medicine*. (<http://tinyurl.com/kg9v25y>)

A Danish study on the link between childhood cancer and assisted reproductive technology found that children born after fertility treatments were 33% more likely to get cancer, while a large-scale British study showed little-to-no correlation between children born after fertility treatments and incidence of childhood cancer.

“FDA Considers Three-Parent IVF” by Jef Akst, *The Scientist*, October 17, 2013

To prevent the passage of mitochondrial disorders from mother to child, researchers have devised a clever solution: take the nucleus of a woman carrying harmful mutations in her mitochondrial DNA and transfer it to an enucleated egg of another woman without such defects. The hybrid egg, which carries the nuclear DNA of the

mother-to-be and healthy mitochondria from the egg donor, can then be fertilized in vitro with sperm from the would-be father, and the resulting embryos implanted into mom. (<http://tinyurl.com/kgdfpm5>)

Despite numerous ethical and safety considerations, three-parent IVF has been approved in Britain and, as of October, the FDA is considering whether to approve it for the U.S. Mitochondrial disease is passed down from the mother to her children because all mitochondrial DNA is passed down through the mother. This technique, while called “three-parent” IVF, involves producing a child whose DNA would be predominantly comprised of the intended mother and father with a small percentage of the child’s DNA from the mitochondria of an egg donor.

“In Syria, Doctors Risk Life and Juggle Ethics” by Sheryl Gay Stolberg and Anne Bernard, *The New York Times*, October 21, 2013

... Syria’s civil war has been especially dangerous for health professionals; a United Nations report issued last month described the “deliberate targeting of hospitals, medical personnel and transports” as “one of the most alarming features of the Syrian conflict.” By varying estimates, more than 100 doctors have been killed and as many as 600 have been imprisoned. (<http://tinyurl.com/lnlhcwmm>)

The World Health Organization reports that Syria’s health system is in complete disarray. Many of the hospitals have been damaged or are no longer functioning. People require basic health needs including vaccinations and insulin. Additionally, doctors must treat people who have been injured from chemical warfare. The humanitarian group, Doctors without Borders, has had to navigate disclosing sensitive information to authorities.

“WHO Responding to Health Needs Caused by Typhoon Haiyan (“Yolanda”) News Release, *World Health Organization*, November 11, 2013

The typhoon – locally known as Yolanda – ravaged the central part of the archipelago Friday morning [November 8] with winds reaching speeds of more than 250 km per hour causing storm surges of up to 5 metres. Many people living in these affected areas were injured and the devastating effects of this typhoon left already vulnerable health facilities damaged or completely destroyed. As a result of the breadth and severity of the storm, health services in the worst affected areas no longer exist or are severely stretched, with medical supplies in very short supply. (<http://tinyurl.com/lolmzwa>)

An important area of bioethics is the special circumstances surrounding natural disasters. In these cases, triage and resource management become key factors in determining the best way to provide medical attention to those in need. This November, the Philippines was devastated by a massive typhoon, which killed thousands of people and destroyed entire towns.

“Condemned Man’s Request to Donate Organs Raises Troubling Ethical, Medical Questions in Ohio” by Julie Carr Smyth and Amanda Lee Myers *Associated Press*, November 14, 2013

An eleventh-hour request by an Ohio death row inmate to donate his organs is raising troubling moral and medical questions among transplant experts and ethicists. (<http://tinyurl.com/mt33pld>)

Ronald Phillips is a convicted murderer in Ohio who wants to donate a kidney to his mother and after his execution, donate his heart to his sister. It is not unheard of for an inmate to donate a non-vital organ, such as a kidney or bone marrow. However, ethicists are concerned over the precedent it would set if inmates are allowed to donate vital organs, and they question whether someone on death row can freely give consent.