Of Note

Withholding Results From Clinical Trials Is Unethical, Says WHO

This April the World Health Organization (WHO) released a statement calling for the results of all clinical studies to be made available to the public. (http://www.who.int/ictrp/results/reporting/en/) Marie-Paule Kieny, an assistant director at WHO, said in a press statement, "failure to publicly disclose trial results engenders misinformation, leading to skewed priorities for both R&D and public health interventions."
WHO recognizes the many reasons for study results to go unpublished: unwanted results, difficulty in obtaining a publisher, and the amount of time it takes to write up a report. However, WHO and others, argue that these challenges can be overcome through more readily available resources. They have created a checklist of what needs to be in a paper in their CONSORT statement found at www.consort-statement.org. They also champion clinical trial registries such as https://www.clinicaltrials.gov which, even though it does not contain as much detail, provides a database from which a broader picture can emerge. The United States and Europe already have made important steps towards trial registration and public reporting. Vasee Moorthy, an author of a paper about the new statement published in *PLOS Medicine*, "hopes the WHO's statement will stimulate countries elsewhere to do the same." Martin Enserink, *Science Magazine*, April 14, 2015.

New Group Pushes to Overhaul Organ Donations

A new group launched in May seeks to reform the process of liver transplants by reducing geographical differences. The group, called the Coalition for Organ Distribution Equity (CODE), consists of hospitals and organ donation organizations. The current system divides the nation into 11 regions based on geography. This creates a disparity in wait times such that California and the Northeast have higher wait times than more rural regions. CODE argues that by reducing the number of regions, "discrepancies in wait times can be reduced and lives can be saved." Leaders in Congress from those overcrowded regions are joining the cause. "Because of disparities in the existing system, patients in our states in need of transplants have disproportionately longer wait times and waitlist mortality rates," according to correspondence from a bipartisan group of senators from those states to the Health Resources and Services Administration. Peter Sullivan, *The Hill*, May 20, 2015.

Genetic Testing is Not Flawless, Study Finds

A new report "from a big private-public project to improve genetic testing reveals it is not as rock solid as many people believe, with flaws that result in some people wrongly advised to worry about a disease risk and others wrongly told they can relax." Study leader, Heidi Rehm,

genetics lab chief at Brigham and Women's Hospital in Boston states, "We have very clear documentation that there are differences in what patients are getting in terms of how tests on the same gene variation are interpreted."

The rise of private mail-in companies offering genetic testing forced the U.S. government several years ago to form and fund ClinVar, a database for researchers around the world to pool gene findings. Currently, more than 300 labs contribute. In May, the group made a report to Washington and published it online through the *New England Journal of Medicine*. This report reveals that "at least 415 gene variants now have different interpretations." It is because of these inconsistencies that patients ought to seek out second opinions. Rehm "described a woman who had genetic testing and wrongly was told she did not have elevated risks for breast cancer. She later developed the disease but could have had preventative surgery had the right gene analyses been done."

Dr. Eric Topol, director of the Scripps Translational Science Institute, believes that with more sharing, the mystery gene variant problem "will largely go away, but that's going to take a few years at least." Marilynn Marchione, *AP*, May 27, 2015.

Industry Growth Leads to Leftover Embryos, and Painful Choices

With the rise of reproductive technologies in the United States, a major ethical dilemma continues to grow regarding the fate of leftover embryos. In 2011 a survey estimated the existence of 612,000 embryos remain in storage. Today, that number could be closer to a million. Unfortunately, there are no statistics on what happens to these embryos. Many sit in storage costing clinics, facilities, or the donor couple $300 - $1,200 a year. A new movement has occurred calling for the donation of these embryos to non-related individuals. Donation has risen from 596 in 2009 to 1,084 in 2013. This has caused the creation of specialty clinics meeting the needs of both donors and infertile couples. Tennessee has The National Embryo Donation Center and Florida has Embryo Donation International. These organizations share a mission to bring leftover embryos and infertile couples together.

One clinic in California, California Conceptions, goes beyond embryo donation to embryo creation. This business seeks out donor gametes whose profiles are most likely to have "broad appeal." They believe that this process along with a money back guarantee will open the field of reproductive technologies to those in lower financial situations. This practice raises legal and ethical questions. States such as New York ban the creation of embryos for reproduction and the American Society for Reproductive Medicine is looking into the ethics of this practice. Tamar Lewin, *The New York Times*, June 17, 2015.

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