U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON SCIENCE, SPACE, AND TECHNOLOGY
SUBCOMMITTEE ON RESEARCH AND TECHNOLOGY

HEARING CHARTER

The Science and Ethics of Genetically Engineered Human DNA

Tuesday, June 16, 2015
2:00 p.m. – 4:00 p.m.
2318 Rayburn House Office Building

Purpose

On Tuesday, June 16, 2015, the Research & Technology Subcommittee will hold a hearing titled *The Science and Ethics of Genetically Engineered Human DNA.* Human gene editing has been a major topic of news and editorials in recent months in both the popular and scientific press.[1] The purpose of the hearing is to review the science behind new gene editing technologies, examine the ethical implications and risks, discuss the promise or potential applications for this new research, and explore how to build a responsible framework for utilizing gene editing technologies. Witnesses will also discuss how the United States can provide scientific and ethical leadership in this arena.

Witness List

Dr. Victor Dzau, President, Institute of Medicine
Dr. Jennifer Doudna, Professor of Biochemistry and Molecular Biology, University of California, Berkeley
Dr. Elizabeth McNally, Director, Center for Genetic Medicine, Northwestern University
Dr. Jeffrey Kahn, Professor of Bioethics and Public Policy and Deputy Director for Policy and Administration of the Berman Institute of Bioethics, Johns Hopkins University

Background

Genome-editing tools that allow a gene to be deleted, inserted, or replaced by a different piece of DNA are becoming more cost-effective and simpler to execute. New gene-editing techniques that can repair or enhance a human gene, are also now capable of altering the human germline – the cells that last for the life of the individual and are passed on to future generations.[2]

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[1] "CRISPR: The Good, the Bad, the Unknown," *Nature* Special Archive. Available at: http://www.nature.com/news/crispr-1.17547
"Scientists are Growing Anxious about Genome-Editing Tools," *Washington Post*, May 18, 2015. Available at: http://www.washingtonpost.com/national/health-science/scientists-are-growing-anxious-about-genome-editing-tools/2015/05/18/0a4db63c-ef4e-11e4-8abc-d6aa3bad79dd_story.html
[2] "A Powerful New Way to Edit DNA," *New York Times*, March 3, 2014. Available at: http://www.nytimes.com/2014/03/04/health/a-powerful-new-way-to-edit-dna.html

Last April, it was reported that a team of Chinese researchers attempted to edit the genome of human embryos for the first time.[3] The team used a new gene-editing technology called CRISPR/Cas9 in an attempt to replace a gene in 86 non-viable human embryos. The technique was successful in only a small fraction of the embryos and caused other unintended genetic mutations.[4] In the wake of the Chinese team publishing their study, the National Institutes of Health issued a statement that in the United States there are "existing legislative and regulatory prohibitions against this kind of work."[5]

Many in the scientific community, including prominent scientists and inventors of gene-editing technologies, have called for a worldwide moratorium on such altering of human DNA.[6] Although these technologies may promise new treatments for inherited genetic diseases such as cystic fibrosis, sickle cell disease and hemophilia, there is also concern that they could be abused to create "designer babies" or alter heritable human DNA in unexpected or dangerous ways.[7]

Precedents for this type of moratorium exist. In 1975, the scientific community agreed on a worldwide suspension on experimenting with new recombinant DNA techniques to manipulate genes, while a safety and ethical framework was developed. The safe and ethical use of this technology later became the underpinning of the biotechnology industry, creating new medical treatments, agriculture products, and biofuels.[8]

Last month, the National Academy of Science (NAS) and Institute of Medicine (IOM, to be renamed the National Academy of Medicine effective July 1st) announced that they were launching a major "Initiative on Human Gene Editing."[9] The organizations are proposing a comprehensive study of the scientific underpinnings and clinical, ethical, legal and social implications of human gene editing. NAS and IOM will also recommend an international symposium of stakeholders to discuss setting guidelines for such genome-editing research.

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[3] "Chinese Scientists Edit Genes of Human Embryos, Raising Concerns," *New York Times*, April 23, 2015. Available at: http://www.nytimes.com/2015/04/24/health/chinese-scientists-edit-genes-of-human-embryos-raising-concerns.html

[4] "Chinese Scientists Genetically Modify Human Embryos," *Nature*, April 22, 2015. Available at: http://www.nature.com/news/chinese-scientists-genetically-modify-human-embryos-1.17378

[5] Statement from Dr. Francis Collins, Director, National Institutes of Health, April 29, 2015. Available at: http://www.nih.gov/about/director/04292015_statement_gene_editing_technologies.htm

[6] "A Prudent Path Forward for Genomic Engineering and Germline Gene Modification," *Science Magazine*, April 3, 2015. Available at: http://www.sciencemag.org/content/348/6230/36

"Let's Hit 'Pause' Before Altering Humankind," *Wall Street Journal*, April 8, 2015. Available at: http://www.wsj.com/articles/lets-hit-pause-before-altering-humankind-1428536400

International Society for Stem Cell Research Statement in support of moratorium. Available at: http://www.isscr.org/home/about-us/news-press-releases/2015/2015/03/19/statement-on-human-germline-genome-modification

[7] "Engineering the Perfect Baby," *MIT Technology Review*, March 5, 2015. Available at: http://www.technologyreview.com/featuredstory/535661/engineering-the-perfect-baby/

[8] NIH Human Genome Project History. Available at: http://www.genome.gov/25520302

[9] National Academy of Sciences and National Academy of Medicine Announce Initiative on Human Gene Editing. Available at: http://www.iom.edu/Global/News%20Announcements/NAS-NAM-Human-Gene-Editing.aspx