

**National Academy of Sciences/National Academy of Medicines
Planning Committee Organizing the International Summit on Human Gene Editing**

**Comments of Jaydee Hanson, Program Director for Human Genetics and Emerging Technologies
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The May 18, 2015 announcement of this NAS/NAM project noted that “recent experiments to attempt to edit human genes also have raised important questions about the potential risks and ethical concerns of altering the human germline. Future advances are likely to raise new questions.”

Unfortunately, there has been little discussion today of any social risks and ethical concerns about human germline engineering. Why is there an entire day dedicated to a “pre meeting” about the scientific and technical aspects of gene editing, but no mention of the social, policy and ethical risks? Moreover, the conference being planned for December seems to primarily be a convening of the scientists from the US, the UK, and China involved in developing and promoting these new technologies.

While gene editing may turn out to be useful for treating people who have certain diseases, there is very little medical justification for using it on future children. That makes this literally a discussion of scientific elites of a new eugenics agenda—not a way to promote trust in these gene editing technologies. I live in the Commonwealth of Virginia where our government just this year has provided reparations to the survivors of the Commonwealth’s 50 yearlong eugenics program that was a model for the Nazi eugenics program.

Instead, we need broad public dialogue where the public can raise concerns about how to use these new technologies. We need space where the public can argue for a more precautionary approach. The scientific community frequently dismisses the concerns of the public as uninformed, after the developers of the technologies define which parts of the debate are proper. Limiting comments to a few minutes at a meeting like this does not signal respect for public sentiment or for different kinds of knowledge. Moreover, for those of us living in democracies, it is a rejection of a responsible relationship between science and democracy, and an endorsement of what amounts to a dictatorship of a commercial technological enterprise. This is unfortunate, because the debate around CRISPR and other gene editing technologies *could* be used as a chance to rebuild

public trust. No one wants the deliberations about human gene editing to become as polarized as the debates on stem cell research and abortion.

Finally, the public invited to help plan future meetings needs to include representatives from communities where women might be used as surrogates for genetically engineered human babies and ethicists and activists from nations and organizations which oppose human germline engineering. More than 120 civil society groups from around the world helped develop the [Principles for the Oversight of Synthetic Biology](#) in 2012. On page 5 of the Principles, these groups specifically call for a prohibition of the use of new genetic engineering techniques to make inheritable changes to the human genome. I commend the Principles to you and have several copies of the Principles for your planning committee.