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11 organizations urge cautious but proactive approach to gene editing

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An international group of 11 organizations with genetics expertise has issued a policy statement on germline genome editing in humans, which recommends against genome editing that culminates in human

pregnancy; supports publicly funded, in vitro research into its potential clinical applications; and outlines scientific and societal steps necessary before implementation of such clinical applications is considered.

Published August 3 in *The American Journal of Human Genetics*, the statement was jointly authored by the American Society of Human Genetics (ASHG), the Association of Genetic Nurses and Counsellors, the Canadian Association of Genetic Counsellors, the International Genetic Epidemiology Society, and the National Society of Genetic Counselors. It was also endorsed by the American Society for Reproductive Medicine, the Asia Pacific Society of Human Genetics, the British Society for Genetic Medicine, the Human Genetics Society of Australasia, the Professional Society of Genetic Counselors in Asia, and the Southern African Society for Human Genetics.

"Our workgroup on genome editing included experts in several subfields of human genetics as well as from countries with varying health systems and research infrastructure," said Kelly E. Ormond, MS, CGC, lead author of the statement and Professor of Genetics at Stanford University. "Given this diversity of perspective, we are encouraged by the agreement we were able to reach and hope it speaks to the soundness and wider acceptability of our recommendations," she said.

The CRISPR/Cas9 system, a genome editing tool introduced in 2013, has quickly become widely used in genetics research due to the ease with which it can be customized and its effectiveness across cell types and species. There is considerable interest in using this tool in somatic cells—to develop cell-based therapeutics, for example—as well as in germline cells, the focus of this statement and an ethically more complex issue because of potential effects on not just the treated individual but also future generations.

"While germline genome editing could theoretically be used to prevent a

child being born with a genetic disease, its potential use also raises a multitude of scientific, ethical, and policy questions. These questions cannot all be answered by scientists alone, but also need to be debated by society," said Derek T. Scholes, PhD, ASHG Director of Science Policy.

After considering these issues and the current state of the science in germline genome editing, the statement authors agreed that:

- At this time, it is inappropriate to perform germline gene editing that culminates in human pregnancy, and
- There is currently no reason to prohibit in vitro (outside of a living organism) germline genome editing research, with appropriate oversight and consent, or to prohibit public funding for such research.

Further, they agreed that before any future clinical application of germline genome editing takes place, there should be:

- A compelling medical rationale to use this approach
- An evidence base to support its clinical use
- An ethical justification, and
- A transparent and public process to solicit and incorporate stakeholder input

"As basic science research into genome editing progresses in the coming years, we urge stakeholders to have these important ethical and social discussions in tandem," said Professor Ormond.

More information: Ormond KE et al. (2017 Aug 3). ASHG policy statement on human germline genome editing. The *American Journal of Human Genetics*. DOI: 10.1016/j.ajhg.2017.06.012