ARRIGE
Association for Responsible Research and Innovation in Genome Editing

Statement from ARRIGE Steering Committee on the possible first gene-edited babies

The gene-editing experiment on human embryos resulting in the birth of the first gene-edited twin girls, possibly conducted in China by the researcher Jiankui He, has shocked the entire scientific community. The ARRIGE Steering Committee wants to express its stern condemnation of these experiments, apparently carried out with no required ethics oversight, review and approval, and without institutional authorizations and permission from authorities. Furthermore, we consider unacceptable from an ethically standpoint the unnecessary high risk this researcher has transferred to these newborns, whose health status will have to be monitored the rest of their lives, including their descendants.

He claims to have implanted gene-edited human embryos resulting in two pregnancies, one of having already reached term with two twin girls born. The aim of this researcher was to inactivate the CCR5 gene in human embryos to render the resulting newborns immune to AIDS virus infection, something we do not know if this is achievable, and in any case for which there are alternative medical treatments not requiring gene edition.

While the new CRISPR gene-editing technology is extremely useful in biomedical research, its current application to human beings is premature, due to the uncertainty of the repaired target alleles and the possibility to alter similar sequences in the genome (off-targets). Moreover, He's primary intention apparently was not to cure human embryos for a given underlying pathology, but to improve the traits of those embryos, a potentially dangerous use leading to eugenics.

The ARRIGE Steering Committee would like to propose the modification of any UNESCO universal declarations, such as the Declaration on the Human Genome, to include a simple additional point clearly stating that the application of human genome edited technologies should not be permitted nor authorized until deemed safe and effective for human beings, with precise therapeutic applications justified after a broad and open debate.

3 December 2018

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