



June 14th, 2019

Common statement between the Association for Responsible Research and Innovation in Genome Editing (ARRIGE), the Genome Writers Guild (GWG) and the Japanese Society for Genome Editing (JSGE)

From Russia, a molecular biologist, Denis Rebrikov, has announced he intends to genome edit human embryos later this year, to inactivate the *CCR5* gene by introducing the genomic deletion, and to implant these gene-edited embryos in the uteri of HIV-infected women. This researcher claims that he has a safer method than used before, enabling him to achieve his goals in more than 50% of the cases. This shocking news comes just seven months after we learned of the first reported case of genome editing of human beings, carried out by a Chinese scientist, without global acceptance and ethical oversight by peers, which was strongly opposed and unacceptable by the scientific community, including the three groups signing this statement.

CRISPR mediated genome editing is a powerful tool to modify the DNA sequence at the target site in the genome, but unfortunately, we are still not able to fully control the output of genome editing experiments. In some cases, unexpected large deletions, insertions, inversions or rearrangements may occur around the targeted site and, perhaps, elsewhere in the genome. From numerous animal experiments, we learned that genome editing can be “mosaic” of some cells in an embryo, which is difficult to control with the current technology. Because of those technical uncertainties, it is unwise and ethically unacceptable to transfer this current risk and uncertainty to human beings. Further discussion is needed to assess the risk-benefit from scientific, medical, ethical, and social points of views, and to the parents and to the babies who will be born without prior consent for editing his/her genomic sequence. For example, the consequences of artificially deleting *CCR5* gene should be carefully investigated, because the recent publication in *Nature Medicine* reported a 21% increase in the all-cause mortality rate in individuals in UK who have homozygous deletion in the *CCR5* gene. Cautious oversight, deliberation, and ethical consideration may in the future allow for safe and reasonable use of genome editing in the human embryos, but as things stand this experiment is highly irresponsible and should be prevented. The authorities should closely monitor the activities of this researcher and others like him who are attempting such irresponsible experiments under hasty consideration.

We - ARRIGE, GWG and JSGE - have joined together in this common statement to strongly request the urgent implementation of a more comprehensive framework for the international regulation of human gene editing activities in embryos, prevent the application of these powerful technologies on human embryos leading to live births before they are deemed safe, helpful and acceptable, and to launch a broad and open debate with all stakeholders, including the public. International agencies such as United Nations or the World Health Organization should also cooperate and work with the sovereign states to promote or update existing universal declarations with the same aim.

The CRISPR genome editing revolution has a tremendous potential to bring benefits and cures to humankind. But its deliberate misuse can also bring uneasiness, anxiety and mistrust. As a society we should stand against any attempt to use these techniques prematurely, dangerously and irreversibly on human beings.