



Committee on Social Affairs, Health and Sustainable Development

Germ-line genome editing in human beings

Declaration adopted by the Committee on 4 December 2018

The Committee on Social Affairs, Health and Sustainable Development of the Parliamentary Assembly of the Council of Europe reiterates the Council of Europe's call for a ban on establishing a pregnancy using germ-line cells or human embryos which have undergone intentional genome editing.

The Committee recalls that the current scientific consensus is that the use of such new genetic technologies in human beings is not safe, notwithstanding the announcement of the purported birth of two babies in China following genome intervention. It also recalls that deliberate germ-line editing in human beings crosses a line viewed as ethically inviolable by the Parliamentary Assembly.

The Committee underlines the urgency of fostering a broad and informed public debate on the medical potential and possible ethical and human rights consequences of the use of new genetic technologies in human beings, emphasizing that the decision whether and when to allow any, let alone clinical use of germ-line genome editing in human beings, should not be left to scientists' discretion and self-regulation.

Background

The Parliamentary Assembly called for a ban on establishing a pregnancy using germ-line cells or human embryos which have undergone intentional genome editing in October 2017 (Recommendation 2115 (2017) on The use of new genetic technologies in human beings), a call which was endorsed by the organisation's Committee of Ministers in February 2018 (Doc. 14503).

The 1997 Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164, "Oviedo Convention"), binding on the 29 member States which have ratified it, posits in its Article 13 that "an intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modifications in the genome of any descendants".

The Second International Summit on Human Genome Editing in Hong Kong took place on 27-29 November 2018. At the summit, a claim was heard that human embryos had been edited and implanted in China, resulting in a pregnancy and the birth of twins. The organizing committee of the second summit issued a statement calling the procedure (if verified) "irresponsible" and not in conformity with "international norms", and reiterated the committee's continued belief "that proceeding with any clinical use of germline editing remains irresponsible at this time. Nevertheless, germline genome editing could become acceptable in the future if these risks are addressed and if a number of additional criteria are met. These criteria include strict independent oversight, a compelling medical need, an absence of reasonable alternatives, a plan for long-term follow-up, and attention to societal effects."

The Council of Europe Committee on Bioethics (DH-BIO), representing 47 European states, issued a statement on 30 November 2018 (attached) underlining that "ethics and human rights must guide any use of genome editing technologies in human beings", and is due to finalise later this month a technical study describing the state of the art of gene editing technologies in human somatic and germ-line cells in the health field and another study providing an overview of the ethical issues at stake.