Question for oral answer O-000013/2019
to the Commission
Rule 128
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on behalf of the PPE Group

Subject: Human germline genome modification

The development of rapidly advancing genome editing technologies, in particular CRISPR/Cas9, has brought significant progress in understanding and addressing serious medical conditions. However, while somatic genome editing advances into its clinical trials phase under rigorous and responsible translational criteria, germline genome editing may give rise to an ambiguous interpretation of the internationally recognised prohibition of human germline modification.

During the recent Second International Summit on Human Genome Editing held in Hong Kong on 27-29 November 2018, the first clinical use of germline genome editing was unexpectedly reported by the Chinese researcher He Jiankui, who claimed that it resulted in the birth of two babies. Although this claim has not been verified, it was at any rate deeply flawed and unethical, as the international scientific community has altogether confirmed.

The germline genome editing of embryos and gametes poses serious risks of unintended harmful effects, not only for the individual, but also for their descendants. Inheritable genetic changes would thus lead to alterations of all future generations. Moreover, this procedure seriously undermines human dignity. The prohibition of germline genome modification is anchored in international agreements such as the Universal Declaration on the Human Genome and Human Rights and the Oviedo Convention, as well as EU law[1].

In light of the above:

1. Is the Commission aware of the urgent need to address the ethical and legal implications of human germline genome modification for the safety of children and future generations and to support, accordingly, a global ban on modifying the human genome in order to forestall unethical human experimentation?

2. What measures does the Commission intend to take to foster broader public engagement and debate based on a correct interpretation of scientific progress in a social context?

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[1] EU Clinical Trials Regulation (EU) No 536/2014, EU Biotech Directive 98/44/EC, Horizon 2020.