

Germline gene therapy is compatible with human dignity

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Reply to: **F Baylis & L Ikemoto**

In our Opinion [1] in reaction to recent research developments towards establishing precise and safe genome editing, we suggested that the Council of Europe, instead of reaffirming an absolute ban on any kind of human germline intervention, as stated in Article 13 of the Oviedo Convention, should start a debate on a less restrictive policy approach, which would allow in principle germline gene therapy in the future. In reaction to our opinion, Baylis and Ikemoto [2] argue that the safety and efficacy of precise germline gene editing are irrelevant to the importance of Article 13 since it is rooted in principles of human rights and dignity (“Neither human rights, human dignity, nor ethics can be peremptorily reduced to safety and efficacy”).

We agree that Article 13 should not be read out of context, but not only as a part of Chapter IV as they point out, but as a part of the whole Convention. According to the Explanatory Report to the Oviedo Convention [3], the absolute ban in Article 13 has been introduced in response to fears of misusing the progress in genetics to “endanger not only the individual but the species itself”. “The ultimate fear is of intentional modification of

human genome so as to produce individuals or entire groups endowed with particular characteristics and required qualities. In Article 13, the Convention provides the answer to these fears in several ways” (par. 89). From this explanation, it is clear that the fear comes not from any interventions into the human germline, but only those that could lead to eugenic consequences.

There is ongoing debate as to how to interpret human dignity in bioethical discourse. There is no general agreement. Critics consider the concept to be vague, even useless in medical ethics [4]. Moreover, it is well known and often criticized that the concept of human dignity is not defined in the Convention despite the fact it is a cornerstone of it. In our Opinion, we did not venture into these troubled conceptual waters.

However, one can argue that the ban on germline gene therapy in Article 13 is in contradiction with one of the motivations of the Oviedo Convention: that progress in biomedicine would be used solely for the benefit of future generations. As formulated in the Preamble, together with concern at the level of the individual and at the level of society, there is also the third level of concern related to the human species. The Explanatory Report explains it in par. 14: “It

is no longer the individual or society that may be at risk but the human species itself. The Convention sets up safeguards, starting with the preamble where reference is made to the benefits to future generations and to all humanity (. . .)”. Would not safe germline gene therapy, which eliminates serious inheritable diseases for the benefit of future generations, be in complete accordance with this interpretation of human dignity? We think so. Efforts at therapy ought proceed. Despite the fears of Baylis and Ikemoto, general worries about the distant possibility of eugenics should not be permitted to hold hostage emerging research to develop cures for the sick and disabled.

References

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