NOTICE TO MEMBERS

Subject: Petition No 1119/2018 by G.L. (Italian), on behalf of Science for Democracy, on EU funding for human genetic research

1. Summary of petition

The petitioner is dissatisfied that the Commission’s proposal for Horizon Europe, the research and innovation programme of the European Union from 2021 to 2027, excludes human genetic research from eligibility for funding. The petitioner argues that this fails to protect and promote scientific progress in the treatment of serious diseases, in line with fundamental human rights, by excluding from funding research that has the potential to lead to the prevention or treatment of such serious genetic conditions.

2. Admissibility

Declared admissible on 4 March 2019. Information requested from Commission under Rule 216(6).

3. Commission reply, received on 6 May 2019

The EU recognises the importance of supporting research for the treatment of genetic diseases through the EU Framework Programmes for research and innovation Horizon 2020 (2014-2020), and the Commission proposal for Horizon Europe (2021-2027)1. Research intended to modify the genetic heritage of human beings that could make such changes heritable, or intended to create human embryos solely for the purpose of research, is not eligible for funding under Horizon 2020. The rules for participation of the Framework Programmes state that no funding shall be granted for research activities which are forbidden

in the Member States, and no activity shall be funded in a Member State where such activity is forbidden.

Currently, 17 Member States ban human germline genetic modification for reproduction. The provisions in Horizon 2020 regarding research involving germline genome editing remain unaltered in the Commission’s proposal for Horizon Europe (Article 14). This is the most appropriate approach for a research programme that supports researchers established in countries with diverse regulatory situations. This position is also in line with the current state of knowledge, as so far no undisputed scientific conclusions have been reached about the safety and efficacy of genome editing. This does not prevent the funding of germline modifying research by Member States (which constitutes the majority of public resources dedicated to research and innovation in the EU) and which is in the hands of individual Member States.

Horizon 2020 supports research with non-heritable genetic changes and this remains unaltered in the Commission’s proposal for Horizon Europe. Funded research covers a broad variety of genetic diseases and technologies. This includes gene therapy approaches, which the EU Framework Programmes for research and innovation have supported with more than EUR 450 million in the last 20 years, including more than EUR 166 million since the start of Horizon 2020. Examples include the Horizon 2020-funded project on advanced T-cell engineered for cancer therapy (ATECT)2, the first successful chimeric antigen receptors T-cell (CAR-T)3 cell therapy for children with leukaemia and the seventh framework programme (FP7) project on advanced cell-based therapies for the treatment of primary immunodeficiency (Cell-PID)4.

Recently, the World Health Organization (WHO) has formed the Human Genome Editing Expert Advisory Committee, which will advise and make recommendations on global standards for governance and oversight of human genome editing. The Commission is in dialogue with the WHO, other international organisations and Member States on approaches for a global governance framework.

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2 https://cordis.europa.eu/project/rcn/110141/reporting/en
3 http://carat-horizon2020.eu/
Conclusion

The Commission proposal for the next framework programme for research and innovation does not impede research for the treatment of genetic diseases and will continue to support somatic genetic alterations whilst germline genome editing remains ineligible for funding. The Commission will continue to monitor and reflect with its partners on the most appropriate global governance for responsible genome editing.