Dr Cor Oosterwijk (EGAN): The patients’ perspective on human germ line editing

Introduction: Besides being the Secretary General of EGAN, my daily job is to managing the National Patient Alliance for Rare and Genetic Diseases in The Netherlands, called VSOP. As such I am, amongst others, a member of the governmental-instituted committee that decides for which medical indications pre-implantation genetic diagnosis (PGD) can be offered in The Netherlands. In addition, I am the father of Martijn, a 25-year old boy with down’s syndrome. We were informed of his condition already early in pregnancy, which has convinced me since then of the value of being offered a real so-called ‘informed ‘reproductive choice’. This will therefore be my main message.

European patients fully support the use of genome editing techniques in basic and translational somatic medical research. When it subsequently comes to the application in humans, safety is an important issue and of course, also patients want medical interventions to be safe, whether it concerns themselves or their offspring. But safety cannot be made absolute either. Like in all medical interventions, the risk-benefit ratio determines whether or not the intervention should take place.

Safeguarding this risk-benefit balance of medical interventions is sufficiently covered by existing international codes, European and national laws, regulations and medical practice. Also gene editing of the germ line for medical reasons is subject to such codes, laws and regulations. Therefore, in the dialogue concerning applications that modify the human germline, one needs to distinguish between arguments because of possible safety risks or adverse outcomes on the one hand, from an opposition based on moral, ethical or religious reasons on the other hand.

If moratoria on germline editing were solely based on safety issues, one could argue that these moratoria are in fact superfluous, since sufficiently covered by existing laws and regulations. Assuming that because of recent innovations, human germ line editing can be done with an acceptable risk-benefit balance at some point in time, only other ethical considerations remain at stake for our dialogue, and we need to focus on their validity.

For almost all of the 6.000 recognised single gene disorders, affecting 5% of the European population, there is currently no cure or effective medical treatment. In addition to the actual physical burden of the disease for themselves and for existing offspring, patients suffer deeply from the psychological burden of passing on their disorder to their children and future generations. This affects their dignity and certainly, they don’t regard the genetic disease, or the fact that they carry the affected gene, to be part of their identity.

I wonder whether everyone who is involved in the ethical and political debate around this issue, is sufficiently aware of this intense physical and psychological burden for millions of citizens and patients in Europe. If nothing is done, suffering and the transmission of the conditions to the next generations will continue. If nothing is done, whereas something can be done because of recent advances in DNA-editing techniques, one becomes responsible. ‘Nature’ or ‘bad luck’ then cannot be blamed anymore. Society becomes responsible. We become responsible.

Putting a ban on germline editing without solid safety arguments or ethical arguments suggests that governments and societies do not trust themselves to being able to establish appropriate governance to regulate germline editing in a ethically sound way.

The dialogue on this theme should stay far away from terms like “eugenics” or “scientists playing for God”. Indeed, it should never happen that others, scientists or governments, determine how affected patients should act, or unnecessarily limiting their reproductive options. Are we willing to give patients a choice based on their own moral values? Therefore, taking into account the fact that all loving parents seek a healthy as possible future for their future child, the debate and communication on this theme should be based on respecting the human right for autonomous, informed decision-making on issues of reproduction. If the embryo deserves protection, to whatever extent, it also needs to be protected from genetic defects that will affect its development during pregnancy or later in life. At the same time, also to enable a real reproductive choice, societies should accept and respect every child and person with whatever genetic condition or handicap, providing optimal medical and social care to the patients and families involved.

Individually, one should not impose one’s own ethical convictions on others. Similarly, neither the EU nor individual Member States should limit the freedom of choice of other Member States by putting a general ban on germ line editing. At least, the subsidiarity principle should apply. Pre-implantation genetic diagnosis raises similar ethical questions as germ line editing and also this is left to the member states, resulting in a diverse EU-regulatory landscape.

Finally, the debate on germline editing could draw our attention away from an even bigger responsibility. Pre-conception programs are urgently needed as integral part of the national health care systems in the Europe, to enable informed reproductive decision making. In fact, this will have much more impact than germ-line modification to prevent genetic disorders, contributing to healthy pregnancies and preventing maternal and childhood mortality and morbidity. If this is our real concern, then we will recognize the urgent need for political action in this broader field of preconceptional and perinatal care.