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Committee on Social Affairs, Health and Sustainable Development

Minutes

of the hearing on "The use of new genetic technologies in human beings" held in Strasbourg on Tuesday, 24 January 2017, from 2.15 to 3.30 pm

The Committee **held** a hearing with the participation of:

- **Ms Mair Crouch,** Geneticist and Academic Lawyer, University of Glasgow, United Kingdom;
- **Ms Anne Forus,** Representative of the Council of Europe Committee on Bioethics (DH-BIO);
- **Mr Cor Oosterwijk,** Secretary General of the Patients Network for Medical Research and Health (EGAN).

Ms Kyriakides, Chairperson, opened the hearing and welcomed the members, experts and guests.

Ms De Sutter, rapporteur, noted that the genetics field had developed exponentially in recent years. In particular, the discovery of the CRISPR-Cas9 technology had made it possible to edit DNA faster, cheaper, and more accurately than before, thus opening new perspectives in terms of genetic disease prevention. Moreover, mitochondrial replacement therapy was offering parents the possibility to avoid passing down their mitochondrial diseases to their offspring.

While these new technologies could potentially lead to outstanding advances in the field of health, they were also raising difficult human rights and ethical questions due to their possible implications. Despite a moratorium on making inheritable changes to the human genome put in place by scientists themselves, and the Convention on Human Rights and Biomedicine (Oviedo Convention) which prohibits interventions seeking to modify the genome of descendants, there had already been clinical applications of the CRISPR-Cas9 technology on non-viable human embryos in China. Moreover, the first babies with genes coming from pronuclear transfer (the three parents' technique) had recently been born in Mexico and in Ukraine respectively. In the latter case, the technique had aimed at rejuvenating the oocyte of an infertile woman. These issues required an urgent political debate with a view to a decision on what was acceptable and what was not.

The rapporteur then addressed the following question to Ms Crouch:

> *"You recently authored an article on mitochondrial replacement therapy – "the three parents' technique" – and the welfare of the child. Could you please outline for us how the use of such a genetic technology can impact on the welfare of the child?"*

[1] Document declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 24 March 2017 in Paris.

See Appendix I for the full text of **Ms Crouch**'s statement in reply to this question.

The rapporteur then addressed the following question to Ms Forus:

> "*You are a former Chairperson of the Council of Europe Committee on Bioethics, and are still a member of the Committee, specialised in the field of genetic technologies. Can you please inform us about the position of the Council of Europe Committee on Bioethics on the use of these genetic technologies in human beings? In particular, could you tell us more about the Committee's recent statement regarding Article 13 of the Oviedo Convention, which establishes that (I quote) '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?'"*

Ms Forus gave a brief introduction on the Oviedo Convention recalling that it aimed at protecting human rights and dignity in areas concerning the applications of biology and medicine. Its Article 13 prohibited deliberate modifications that could be transmissible to descendants (hence excluding modifications that could result from interventions like chemotherapy or X-ray treatment). Despite their considerable potential benefit for human health, the new genome editing technologies were raising concerns because of their possible misuse (e.g. for enhancement purposes), as well as in terms of their safety (i.e. owing to the unknown risks inherent to the introduction of modification in the genome that would be passed on to the offspring). The DH-BIO had underlined these issues in a statement adopted in December 2015. Recalling the need to have a debate on issues raised by new technologies, the DH-BIO had also suggested that the Oviedo Convention provided principles that could be used as a reference for such a debate. **Ms Forus** concluded by welcoming the timely action of the Assembly in addressing this important matter.

[Ms Forus' PowerPoint presentation is available on the Committee's extranet page.]

Finally, the rapporteur addressed the following question to Mr Oosterwijk:

> *"Can you please inform us about the position of the patients' network you represent on the use of genetic technologies in human beings? In particular, are you in favour of introducing modifications in the germline of human beings to avoid the next generation being born with a hereditary genetic disease?"*

See Appendix II for the full text of **Mr Oosterwijk's** statement in reply to this question.

The Chairperson thanked the experts and in particular Mr Oosterwijk for sharing his personal story with the Committee, which allowed members to put this technical matter into a "reality" perspective.

Mr Davies thanked the experts for their enlightening presentations. He had retained in particular that there was a difference between removing and reducing risks, that there were both known and unknown risks associated with new technologies and that ensuring that patients have a free choice was important. He added that there was also a difference between causing death and saving a life. He welcomed the discussion on this important issue and agreed with the rapporteur on the need to regulate it.

Baroness Massey also agreed on the need to regulate the use of these new technologies. She wondered how the risk associated with the new technologies could be reduced and why there was no legal obligation to monitor children born from the three parents' technique.

Mr Mullen asked about the implications of germline editing for the embryo. He also wondered whether the Oviedo Convention provided for an immediate obstacle to genome editing technologies. He challenged the principle of freedom of choice considering that the latter could have implications for other human beings. To illustrate this, he referred to an article claiming that there would be no more children with Down's syndrome in Denmark by 2030 and asked Mr Oosterwijk's position on this.

Ms Bonet asked whether there were any examples where the modified gene had been passed to the offspring.

Mr Essl argued that it would be impossible to ensure that new technologies would be used for therapeutic purposes only. These technologies would ultimately be used to create the “perfect child”.

Ms Crouch expected that the legalisation of the three parents’ technique in the United Kingdom would generate important health tourism. It would therefore be practically impossible to follow-up all children born from this technique with a view to evaluating its risks. Much was unknown about the outcome of the technique, including its success of “freeing” the offspring from the relevant disease.

Ms Forus said that the impact on future generations was one of the main issues at stake. Establishing a regulatory framework was therefore very important.

Mr Oosterwijk believed that scientists worked to improve human life. Society should trust in its ability to prevent abusive use of new technologies. With good regulation and governance, it was possible to prevent such abuses. In reply to Mr Mullen, he stressed that free and informed choice meant non-directive choice, a choice that the patient would be comfortable with not only at the present time but also in the future. Stressing that Denmark had a non-directive regulation, he said that only 50 % of women chose to abort for reasons related to the health of the baby.

Ms De Sutter noted that there were tensions between reproductive autonomy, the welfare of the child and risks associated with new technologies. The Oviedo Convention put an emphasis on the element of intention (i.e. the aim should not be to introduce any modifications in the genome of any descendant). Therefore, it was not clear whether the prohibition of the Convention was applicable to interventions aimed at curing and preventing genetic diseases, even though they would imply a modification in the genome of the descendant.

List of decisions

The Committee on Social Affairs, Health and Sustainable Development, meeting in Strasbourg on 24 January 2017, with Ms Stella Kyriakides (Cyprus, EPP/CD), Chairperson, in the Chair, as regards:

- **The use of new genetic technologies in human beings (***Rapporteur: Ms Petra De Sutter, Belgium, SOC):* held a hearing with the participation of:

    - Ms Mair Crouch, Geneticist and Academic Lawyer, University of Glasgow, United Kingdom;
    - Ms Anne Forus, Representative of the Council of Europe Committee on Bioethics (DH-BIO);
    - Mr Cor Oosterwijk, Secretary General of the Patients Network for Medical Research and Health (EGAN).

Appendix I

Statement of **Ms Mair Crouch**, Geneticist and Academic Lawyer, University of Glasgow, United Kingdom

Some families are affected by a genetic condition caused by mutation of the mitochondrial DNA of the mother. As you all know the UK has passed a law that allows the use of mitochondrial replacement technique as a form of treatment to prevent the birth of a child with the mutated mitochondrial DNA.

Much of the debate leading to this decision within the UK emphasised the needs of the parents and there was less emphasis on the needs of the child to be created.

There is an obligation within the UK on the clinics offering IVF treatment to consider the welfare of the future child. This is found within Section 13(5) of the Human Fertilisation and Embryology Act 1990 (as amended in 2008).

> Section 13 (5): A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of a child for supportive parenting), and of any other child who may be affected by the birth).
> Section 2 (1) (…) Treatment services means medical, surgical or obstetric services provided to the public or a section of the public for the purpose of assisting women to carry children.

The regulator of fertility treatment and research, the Human Fertilisation and Embryology Authority (HFEA), of which I was a member from 2008 to 2013, provides a Code of Practice and the guidance within needs to be followed by the clinics.

Section 8 of the Code of Practice outlines the factors to take into account during the assessment process for the mandatory requirement to consider the welfare of the child:

> 8.10 The centre should consider factors that are likely to cause a risk of significant harm or neglect to any child may be born or to any existing child of the family. These factors include any aspects of the patient's or (if they have one) their partner's:
>
> b) Past or current circumstances that are likely to lead to an inability to care throughout childhood for any child who may be born, or that are already seriously impairing the care of any existing child of the family, for example: [this brings another issue of the health of the mother who carries the mutation into play as the mother's health could deteriorate due to an expansion of the mitochondria with the mutated mtDNA thus making it difficult for her to be a parent].
>
> i) mental or physical conditions
> iii) medical history, whether medical history indicates that any child who may be born is likely to suffer from a serious medical condition, [this of course could be an indicator to carry out the technique under consideration], or
> iv) circumstances that the centre considers likely to cause serious harm to any child mentioned above.

The HFEA recommended that the techniques could be used for treatment providing "it is safe enough to offer in a treatment setting and is done so within the regulatory framework (…) ethical concerns are outweighed by the arguments in favour of permitting mitochondria replacement".

However, concerns about the risks to the child exist and the welfare of the child need to be considered. For instance, the report produced in the USA by the Institute of Medicine: mitochondrial replacement techniques: ethical, social, and policy considerations placed the safety of the child is paramount (February 2016).

The regulations were brought in to remove risk. The regulation does recognise that organelles in the cytoplasm can be carried over when transferring pronuclei. If this material carried over from the cytoplasm includes mitochondria with mutated DNA into the new embryo created, then it becomes a reduction of risk.

The main driving force in the UK has been Prof Sir Doug Turnbull and his team at the Newcastle centre for life. In a major research paper published in Nature in June of last year there was confirmation that mitochondria with mutated DNA are carried over during the technique of pronuclei transfer.

Over 500 donated eggs were used and the results are troubling as many of the embryos created contained mitochondria carrying the genetic mutation acquired from the maternal egg. They established some embryonic stem cell lines and discovered that within some of these there was expansion of the mutated mitochondria so at present it would appear that at best the technique on offer is a reduction in risk. This suggests that any child born will require prenatal testing to assess the level of mutated mitochondrial in some of the tissues; for the health of the child to be monitored possibly throughout life, and for the child if female warned that any of her future children could be affected by the same condition. This would mean a requirement for the further mitochondrial replacement technique to be carried out in the next generation.

Other risks of the technique exist. 1500 genes in nuclear DNA are associated with the mitochondria. The complex relationship with mitochondrial DNA and with nuclear DNA are not known and research about the relationship is only just beginning to be done. There is a suggestion of a risk from non-compatibility of the haploidy of the donated mitochondria with that of the maternal embryo.

A growing body of evidence suggests that mitochondria do not just produce energy, but also influence a wide range of cellular processes, from cell death to immune responses, and that variations in the organelle matter very much. Variance in mitochondrial DNA are now linked to many common human conditions including neurodegenerative diseases, cancer and ageing. The effects of these variants may come about through the organelle's long evolve partnership with a much larger nuclear genome. The evidence should raise questions about the safety of a procedure that will soon be used in humans.

Further, damage to the structure of the embryo may occur during the procedure; the risks from the reagents; the requirement to use a virus during the procedure, and the freezing of the maternal egg to be in phase with the donor egg.

The UK also decided to suggest that the donation of mitochondria can be equated with organ or tissue transplantation. This is a strange position to hold as mitochondria have a genetic identity with links to the wider biological family, past, present and future.

The decision was also made that the child would not be able to receive the identity of the donor. Denial for the child to know the identity of the donor could lead to psychological harm.

During the debate in Parliament, it was suggested that the regulations should only be introduced once the safety of the technique(s) had been established but the technique was brought into law in the UK before the safety assessment.

Mitochondrial replacement technology is experimental and there is very limited information about safety and efficacy. As with any germline intervention, there are significant and legitimate concerns about the health and well-being of future children and the potential short and long-term harm to them and their progeny.

The techniques being proposed in the UK are prohibited under many international laws. The reason is that altering the germline of future children raises profound safety and ethical concerns. The risk exists that unpredictable consequences will be transmitted to subsequent generations and become irreversibly part of their genome. There are serious concerns that this would set a precedent for further genetic alterations of human beings.

There has been much discussion in the past whether the HFEAct should ever have included a consideration of the welfare of the child, and that this matter should have been left to reference to the UK's Children's Act Section 1 and the Children (Scotland) Act Section 14.

However it is important to go back to the debates prior to the establishment of the HFEAct in 1990 when the most important criterion under discussion then, which led to the inclusion of consideration of the welfare of the child, was the risk to the child of a new technology. This applies as much today when we consider the impact of the new genetic modification technologies on the human embryo.

Appendix II

Statement of **Mr Cor Oosterwijk**- Secretary General of the Patients Network for Medical Research and Health (EGAN).

The patients' perspective on human germline editing.

Besides being the Secretary General of EGAN, my daily job is to manage 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. However, 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 germline 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 germline 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 do not 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 an ethically sound way.

The dialogue on this theme should stay far away from terms like "eugenics" or "scientists playing God". Indeed, it should never happen that others, scientists or governments, determine how affected patients should act, or unnecessarily limit 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 germline editing. At least, the subsidiarity principle should apply. Pre-implantation genetic diagnosis raises similar ethical questions as germline 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 programmes 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 germline 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 recognise the urgent need for political action in this broader field of preconceptional and perinatal care.

AS_SOC/ 2016/BIL/LISTS
24 January 2017

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Ms / *Mme* Mair CROUCH ……Geneticist and Academic Lawyer University of Glasgow, United Kingdom / .....*Généticienne et professeure de droit de l'Université de Glasgow Royaume-Uni*
Ms / *Mme* Anne FORUS.....Representative of the Council of Europe .....Committee on Bioethics (DH-BIO) / .....*Représentante du Comité de Bioéthique* ..... *du Conseil de l'Europe (DH-BIO)*
Mr / *M.* Cor OOSTERWIJK ……..... Secretary General of the Patients Network ..... for Medical Research and Health (EGAN) / .....*Secrétaire Général du Réseau de patients* .....*pour la recherche médicale et la santé (EGAN)*

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