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Committee on Social Affairs, Health and Sustainable Development

Minutes

of the hearing on “Anonymous donation of sperm and oocytes: balancing the rights of parents, donors and children” held in Lisbon, Portugal, on Monday, 17 September 2018, from 3 to 5.30 pm

In the framework of the report currently in preparation on “Anonymous donation of sperm and oocytes: balancing the rights of parents, donors and children” (Rapporteur: Ms Petra De Sutter, Belgium, SOC), the Committee held a public hearing with the participation of:

- Ms Carla Maria Pinho Rodrigues, President of the National Council of Medically Assisted Procreation of Portugal;
- Mr Miguel Oliveira Da Silva, member of the Committee on Bioethics of the Council of Europe (DH-BIO), Portugal;
- Ms Joanna Rose and Mr Christophe Masle, donor-conceived persons;
- and via telephone, in order to preserve anonymity, N.N., donor.

The Chairperson opened the hearing and welcomed the experts.

The Rapporteur, **Ms De Sutter** recalled that in Council of Europe member states there were different types of legislation on sperm and oocyte donation for treatment using assisted reproductive technologies. While donor anonymity was banned in some countries, it was the rule in others. From a human rights perspective, there was a need to find a balance between the rights of all parties concerned, i.e. donors, donor-conceived children/persons and legal parents. She pointed out that current developments, in particular in the field of genetic technology, could soon make anonymity an illusion.

Ms Rodrigues described the situation in Portugal following the April 2018 decision of the Constitutional Court which established the right of donor-conceived persons to know their genetic identity and gamete donors.² Prior to that decision, the 2006 Portuguese law provided for a (quasi) absolute anonymity for donors, as anonymity could only be waived where there was a risk of consanguinity. The Parliament would have to handle the transition from the old system to the new one, by addressing a number of difficult questions, including the fate of cryopreserved gametes donated (and embryos created) before the Constitutional Court's decision, as well as whether anonymity would be waived retroactively or not. Donors under the old regime had already been given the choice to either authorise the disclosure of their identity or “invalidate” their donation. While legislating, the Parliament would have to find a solution balancing the rights of all concerned.

Mr Da Silva presented his personal opinion on the developments in Portugal since the Constitutional Court's decision, which had established that the right to know one's genetic identity and gamete donors came before the donors' right to anonymity and the parents' right to “family peace”. Notwithstanding the Court's decision, the end of anonymity was unavoidable as it was possible, thanks to genetic testing, to find out about one's

¹The minutes were approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 11 October 2018 in Strasbourg.

² Portugal's Constitutional Court held that anonymous gamete donations were unconstitutional, thereby changing the legal situation regarding donations in Portugal.

origins. Studies had shown that a vast majority of children would at least want to have the right to know that they were donor-conceived. Mr Da Silva noted that the Constitutional Court's decision had had no effect on donor recruitment: this could partly be explained by the amount of the compensation received (843 euros per donation) which could constitute a strong incentive for certain donors. A large and informed citizen debate was needed, including on issues such as compensation and the maximum number of donor-conceived children allowed per donor. Mr Da Silva also stressed that relevant decision-making bodies should not have conflicts of interests.

[Mr Da Silva's PowerPoint presentation is available on the PACE Extranet.]

Mr Masle (from France), who has created an association of donor-conceived persons to discuss a third way of making non-identifying information available, was not in favour of lifting anonymity. He considered that assuring emotional and physical security to a child was more important than transmitting his/her genetic material. Therefore, he did not feel comfortable with concepts such as "biological father", half brother or sister. Mr Masle stressed that there could be no real debate around anonymity without first ensuring that at least a majority of donor-conceived people knew about the way they were conceived. In this respect, he noted that only a handful of the 70 000 donor-conceived children in France knew about their way of conception. Amongst them, those emotionally traumatised by their donors' anonymity were only a minority. Elaborating on the non-identifying information to be disclosed, he noted that such data could include the donor's motivation for donating, age, social and professional background, amongst other things.

Ms Rose (from the United Kingdom) was in favour of lifting donor anonymity which had an unavoidable emotional backlash on the donor-conceived person. Referring to Australia's Narelle's law (named after Narelle Grech who had to search for her biological father for fifteen years and died from a genetically-transmitted cancer soon after she found him) which had waived anonymity retroactively, she stressed that access to the donor's identity was a fundamental aspect of the child's identity building, necessary for health reasons as well as to avoid consanguinity. Donor-conceived children's birth certificates were problematic as they were intentionally deceiving them by identifying their social parents as their father and/or mother. Ms Rose raised the issue of conflicts of interest and regretted the presence of infertility industry representatives in committees/bodies mandated to take position on the issue of anonymity, whereas donor-conceived persons were not represented on such bodies. A paradigm shift was needed in reproductive technology, from adult centric 'treatment' to applying normative standards for protecting the best interests of the child.

[Ms Rose's PowerPoint presentation is available on the PACE Extranet.]

In reply to **Ms De Temmerman's** question concerning his contacts with children conceived with his sperm, **an anonymous donor** (from France) explained that one of his biological children had managed to get in touch with him. They had had regular contacts and had also met physically, which he described as being an extremely emotional experience. He did not regret at all that his anonymity had been waived, and encouraged the Council of Europe to go with the time, and let people have a choice.

The low quality of the phone connection did not enable the anonymous donor to reply to **Ms De Sutter's** question on whether he would have chosen to donate should his anonymity not have been guaranteed.

Mr Mullen stressed the complexity of the issue and wondered whether children's choices should have priority over other considerations. If so, was there a right to be informed about one's way of conception, knowing that this information could have adverse effects on the child? Moreover, while deciding the fate of donated gametes, ethical considerations should be taken into account.

Ms Estrela didn't have a clear stand on the issue of anonymity. She wondered how legislation could reconcile contradictory interests and whether it would be possible to authorise donation from healthy individuals only to mitigate health-related implications of anonymous donation.

Ms de Courson wondered whether parents of donor-conceived children should have a duty to inform their children about the way they were conceived.

Mr Essl asked as of when the child had rights.

Ms Mergen asked whether anonymity was still guaranteed for those who had donated prior to the Constitutional Court's decision in Portugal. While she thought that parents should tell their children about their way of conception, she did not know when would be the right time to do so.

Ms Frith, from the Department of Health Services Research of the University of Liverpool, explained that anonymity had been removed in the United Kingdom but not retroactively as it had been the case in Victoria in Australia. She thought that the issue was less of a taboo and donor-based conception was starting to become just another way of forming a family.

Mr Masle thought it was important to ensure that the debate was evidence-based: arguments should not be based on myths around risks of genetically-created illnesses or blood relations marrying. In fact, half of potential donors were refused due to their medical history. His health-related problems were inherited from his mother and his donor's medical file was entirely clean. He stressed that genetic risk was inherent to conception. There was a clear difference between adopted children or children abandoned at birth (mothers delivering under anonymity in France (*accouchement sous X*)) and donor-conceived children, as in the latter case, there was no element of "abandonment". With regard to consanguinity, he noted that three to four per cent of children in France were born out of adultery. Hence, as a donor-conceived child (out of 70 000 in France) he had less chance of marrying his half-sister than those who were not. He also refuted the allegations that most donor-conceived people would be in favour of lifting anonymity, should they know about the way they were conceived. In his association, there were only three people who were in favour of lifting anonymity, all of whom had a missing paternal figure.

Ms Rodrigues clarified that there had not been any problems concerning genetically-created illnesses or blood relations under the Portuguese law, as it had always authorised genetic identity to be revealed when there was a risk for health or of consanguinity. The current difficulties related to the on-going transitional period whereby the country was switching from a system of quasi-full anonymity to one of full transparency. For donations made before the Court's decision, these included questions like who would have access to the donor's information and when, whether they could contact their donor or his/her family etc. A change of mind set was also needed as such issues were still taboo in the Portuguese society. A public symposium with the participation of different stakeholders was envisaged with a view to discussing those different issues.

Mr Da Silva thought that donor-conceived children's wishes should prevail. According to most studies, the majority of children wanted to have the right to know. There was no real right time for it, as children of the same age could be very different in terms of their intellectual and emotional development. He also noted that while donors were indeed screened, their health status could never be entirely guaranteed, as screening was based on today's medical knowledge.

Ms De Sutter, the Rapporteur, was thankful for a long and intense hearing which had proved members' high interest in the topic. In the preparation of her report, she committed to take into account all the different arguments.

The Chairperson thanked the experts and members for their contributions and closed the hearing.