



**Provisional version**

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## **Committee on Social Affairs, Health and Sustainable Development**

# **Anonymous donation of sperm and oocytes: balancing the rights of parents, donors and children**

Rapporteur: Ms Petra De Sutter, Belgium, SOC

### **Report<sup>1</sup>**

#### **I. Draft recommendation<sup>2</sup>**

1. It is estimated that more than 8 million children worldwide have been born as a result of assisted reproductive technologies (ART), many of whom have been conceived of sperm or oocyte donation. Traditionally, most countries favoured anonymous donation models, as legislation in this area was often derived from legislation in the organ donation or international adoption field. Most states thus restricted the right of donor-conceived persons to know their origins.

2. International and European human rights law – including the UNCRC and the case-law of the European Court of Human Rights – has, in the last decades, moved towards recognition of a right to know one's origins, connected to the right to an identity and to personal development. This right includes the right to access information that would make it possible to trace one's roots, to know the circumstances of one's birth and to have access to certainty of parental filiation.

3. However, this right is not absolute and must thus be balanced against the interests of the other parties involved in sperm and oocyte donation: principally those of the donor(s) and the legal parent(s), but also those of clinics and service-providers, as well as the interests of society and the obligations of the State.

4. This balancing of the different rights, interests and obligations has until recently often tended to favour the donor's right to privacy, and therefore, donor anonymity. However, several European countries have decided to waive donor anonymity, and one state (Victoria in Australia) has abolished donor anonymity completely and retrospectively, having come to the conclusion that the state had a responsibility to provide all donor-conceived people with an opportunity to access information, including identifying information, about their donors.

5. The distinguishing features of the Council of Europe, namely its mandate encompassing the promotion of human rights, democracy and the rule of law, and its role of promoting good practice among the member states, places the Organisation in an ideal position to address the risks and challenges related to the anonymity of sperm and oocyte donations. The Parliamentary Assembly thus recommends that the Committee of Ministers make recommendations to member States in order to improve the protection of the rights of all the parties concerned, while focusing on the rights of the donor-conceived person, who is in the most vulnerable position and for whom the stakes appear to be higher.

6. The Assembly invites the Committee of Ministers to deliberate on whether these recommendations should ultimately become legally binding.

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<sup>1</sup> Reference to Committee: Doc. 14419 Reference no. 4349 of 22 January 2018.

<sup>2</sup> Draft recommendation adopted unanimously by the Committee on 21 January 2019.

7. Whichever form the recommendations take, the Assembly advises that they be built on the following principles:

7.1. Anonymity should be waived for all future gamete donations in Council of Europe member States, and the use of anonymously donated sperm and oocytes should be prohibited. This would mean that (except in exceptional cases, when the donation is from a close relative or friend), the donor's identity would not be revealed at the time of the donation to the family, but would be revealed to the donor-conceived child upon his or her 16<sup>th</sup> or 18<sup>th</sup> birthday. The donor-conceived child would be informed at that time (ideally, by the State) that there is supplementary information available on the circumstances of his/her birth. The donor-conceived person could then decide whether and when to access this information containing the identity of the donor, and whether to initiate contact (ideally after having had access to appropriate guidance, counselling and support services before making a decision).

7.2. The waiving of anonymity should have no legal consequences for filiation: the donor should be protected from any request to determine parentage or an inheritance or parenting claim. The donor should receive appropriate guidance and counselling before he/she agrees to donate and his/her gametes are used. The donor should have no right to contact a child born from donation, but the donor-conceived child should be given the option to contact the donor, as well as possible half-siblings, after their 16<sup>th</sup> or 18<sup>th</sup> birthday – subject to certain conditions being met.

7.3. Council of Europe member States which permit sperm and oocyte donation should set up and run a national Donor and Donor Conceived Person Register with a view to facilitating the sharing of information as stipulated in paragraphs 7.1. and 7.2., but also with a view to enforcing an upper limit on the number of possible donations by the same donor, ensuring that close relations cannot marry, and tracing donors if the medical need should arise. Clinics and service-providers should be required to keep and share adequate records with the registers, and a mechanism should be established to provide for cross-border information exchange between the national registers.

7.4. The anonymity of gamete donors should not be lifted retrospectively where anonymity was promised at the time of the donation, except for medical reasons or where the donor has consented to the lifting of the anonymity and thus inclusion on the Donor and Donor Conceived Person Register. Donors should be offered guidance and counselling before they decide whether or not to agree to the lifting of anonymity.

7.5. These principles should be applied without prejudice to the overriding consideration that gamete donation must remain a voluntary and altruistic gesture with the sole aim of helping others, and thus without any financial gain or comparable advantage for the donor.

## II. Explanatory memorandum by the Rapporteur, Ms Petra De Sutter

### 1. Introduction

1. Assisted reproduction using donor sperm has been in place for several decades. The European Society of Human Reproduction estimates that there are more than 8 million children worldwide born as a result of assisted reproductive technologies (ART).<sup>3</sup> In Council of Europe member states there are different types of legislation on human gamete donation, i.e. sperm and oocyte donation for treatment using ART.

2. Traditionally, most states have restricted the right of a person born as a result of artificial insemination by donor sperm (AID) to know their origins. This restriction may be due to legislation, but also to the absence of a system for gathering information on the identities of donors. In the same way as similar legal proceedings on adoption, in cases concerning assisted procreation using human gametes a conflict between the child's right to information and the adult's right to anonymity has typically been resolved in favour of the adult.

3. The anonymity of gamete donors was introduced in the law of many states to ensure that donations would remain altruistic and voluntary, and also to guarantee respect for the donor's private life and the interests of the legal family of the donor-conceived person. It would seem, however, that these grounds for the principle of donor anonymity are now, to some extent, obsolete. The principle of the anonymity of human gamete donors is today called into question by the increasing number of challenges thereto, by changes in society and by the evolution of genetic technology.

4. The Committee held a public hearing on the subject in Lisbon (Portugal) on 17 September 2018, 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, Portugal), two donor-conceived persons and an anonymous donor.<sup>4</sup>

5. In this report, I intend to give an overview of the international/ European legal framework and of the issues at stake. From a human rights perspective, there is a need to find a balance between the rights and interests of all parties concerned, i.e. donors, donor-conceived children/persons and legal parents, clinics and service providers, as well as the interests of society and the obligations of the State.

### 2. The international/ European legal framework: gradual recognition of the right to know one's origins

6. The anonymity of human gamete donors is no longer a principle unanimously adhered to at European level. Internationally, a tendency towards recognition of a donor-conceived person's right to know their origins has been emerging for a number of decades. In 1984, Sweden was the first country to waive the principle of the anonymity of gamete donations.<sup>5</sup> The Swedish example was then followed by several other countries such as Germany, Switzerland, the Netherlands, Austria, Finland, Iceland and the United Kingdom. Recently, Portugal's Constitutional Court held that anonymous gamete donations were unconstitutional, thereby changing the legal situation regarding donations in Portugal and conferring force of law on the right of access to one's genetic origins.<sup>6</sup> There is therefore a growing tendency to give priority to the rights of donor-conceived persons to know their origins and to favour waiving the anonymity of gamete donors.

7. Several international instruments reflect this development. Firstly, Article 7.1 of the United Nations Convention on the Rights of the Child (CRC) of 20 November 1989 provides for a child's right to know his

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<sup>3</sup> See article in Science News Daily, More than 8 million babies born from IVF since the world's first in 1978, 3 July 2018, <https://www.sciencedaily.com/releases/2018/07/180703084127.htm>. I have not been able to find a reliable estimate on how many of these births involved donor sperm or oocytes. For a critique of the status quo, see: Wendy Kramer, 30k-60k US Sperm and Egg Donor Births Per Year?, Huffington Post, 10 June 2015.

<sup>4</sup> The minutes of this hearing have been declassified and are available on the PACE website (AS/Soc (2018) PV 05 add).

<sup>5</sup> Law No. 1140 of 20 December 1984 on artificial insemination

<sup>6</sup> Decision of the Constitutional Court (Portugal), 24 April 2018, No. 225/2018

or her parents "as far as possible".<sup>7</sup> Article 8 of the CRC also establishes the right of the child to preserve his or her identity, including family relations, without unlawful interference. It goes on to provide that states shall grant appropriate assistance and protection with a view to speedy re-establishment of the child's identity.<sup>8</sup> However, it should be noted that the CRC applies solely to "children".<sup>9</sup> Its scope does not extend to adults conceived through gamete donation who wish to know their genetic origins.

8. In the somewhat-related field of international adoption, the widely-ratified Hague Convention on protection of children and co-operation in respect of intercountry adoption posits, in its Article 30:

"(1) The competent authorities of a Contracting State shall ensure that information held by them concerning the child's origin, in particular information concerning the identity of his or her parents, as well as the medical history, is preserved.

(2) They shall ensure that the child or his or her representative has access to such information, under appropriate guidance, in so far as is permitted by the law of that State."<sup>10</sup>

It can certainly be argued that the situation of donor-conceived persons is closer to that of children who have been adopted across borders than to recipients of organ donation.<sup>11</sup>

9. The Council of Europe's European Convention on Human Rights (ECHR) may also be useful in this respect, in that it applies to all persons, whether a minor or an adult. Since the early 2000s the Strasbourg-based European Court of Human Rights has given a constructive interpretation to Article 8 of the Convention which provides for a person's right to respect for private life. It has, for example, held that Article 8 protects "the right to an identity and to personal development", which includes the right to access information that would make it possible to trace "some of [one's] roots".<sup>12</sup> It has also held that Article 8 implies the right of a person to know their origins and the circumstances of their birth<sup>13</sup> and a right to have access to certainty of paternal filiation.<sup>14</sup>

10. The Court thus places emphasis on the vital interest of the child, even as an adult, to obtain information essential to discovering the truth about an important aspect of their personal life, which includes the identity of their genitor. However, as reflected in the Court's judgments, the right to know one's origins is not absolute and must always be balanced against the interests of the other parties concerned. What is striking is that this balancing often tends to favour the genitor's right to privacy, and therefore, donor anonymity.<sup>15</sup> In

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<sup>7</sup> Article 7 has been interpreted by the Committee on the Rights of the Child as including the right of children born through assisted reproduction technologies involving a third party to have access to information about their biological family in accordance with the legal and regulatory framework of the country concerned. See the Concluding Observations of the Committee on the Rights of the Child concerning the report by Ireland, 1 March 2016 (CRC/C/IRL/CO/3-4, paragraphs 33-34.) In fact, the Committee noted the possible contradiction between Article 7 of the Convention and the policy of a state party (Norway) in relation to insemination by donor, "namely in keeping the identity of sperm donors secret", already in 1994 (CRC/C/15/Add.23). For further information on the interpretation of the CRC, please refer to: Brigitte Clark, A Balancing Act? The Rights of Donor-Conceived Children to Know their Biological Origins, *Georgia Journal of International and Comparative Law*, Volume 40, 2012, no. 3, pp. 625-629.

<sup>8</sup> Sonia Allan cites the Implementation Handbook of the Convention with respect to this Article: "Thus children's best interests and senses of identity may be sustained without having to deny them knowledge of their origins, for example after reception into state care, through "secret" adoptions or anonymous egg/sperm donations and so forth." Sonia Allan, Guest editorial on Donor conception, secrecy and the search for information, Article in *Journal of law and medicine*, June 2012, p. 641.

<sup>9</sup> Within the meaning of Article 1 of the Convention on the Rights of the Child (CRC), a child means every human being below the age of 18 years unless under the law applicable to the child, majority is attained earlier.

<sup>10</sup> <https://assets.hcch.net/docs/77e12f23-d3dc-4851-8f0b-050f71a16947.pdf>

<sup>11</sup> For example, Sonia Allan, in her Guest editorial on Donor conception, secrecy and the search for information, explained:

"Psychologists have drawn many parallels between the experiences of donor-conceived people and adoptees, particularly in relation to the problems described above that some people experience in relation to genealogical bewilderment as a result of being denied access to information, and the secrecy that in the past shrouded both practices." *Op. cit.*, p. 643.

<sup>12</sup> Judgment of the European Court of Human Rights of 25 September 2012, No. 33783/09, *Godelli v. Italy*

<sup>13</sup> Judgment of the European Court of Human Rights of 13 February 2003, No. 42326/98, *Odièvre v. France*

<sup>14</sup> Judgment of the European Court of Human Rights of 13 July 2006, No. 58757/00, *Jäggi v. Switzerland*

<sup>15</sup> In the above-mentioned *Odièvre v. France* judgment, which concerned an application by a person whose mother had opted to give birth anonymously, requesting access to information on their biological family, the Court, after having established the principle of the right to access information, held nonetheless that the French legislation which provides for the right to give birth anonymously did not violate Article 8 of the ECHR in that it tends to strike a balance and ensure sufficient proportion between the competing interests.

addition, none of the Court's decisions so far have specifically concerned the right of a person conceived by means of gamete donation to have access to information on the donor, although a number of applications are currently pending (against France) on this subject.<sup>16</sup> It is therefore not possible for the moment to establish with certainty whether or not the Court is in favour of waiving donor anonymity.<sup>17</sup>

11. In view of what can be perceived as the limited scope of international instruments guaranteeing the right to know one's origins and of the remaining disparities between national laws, which are likely to increase recourse to cross-border medically assisted procreation, the Assembly should draw attention to the existing inadequacies and make recommendations regarding the steps that might be considered by Council of Europe member states and the Council of Europe itself in order to clarify the situation and find the best balance.

### 3. The issues: the various problems posed by anonymous donation of gametes

12. The anonymity of gamete donors raises a number of issues, which lead to the question of whether it should be maintained in the legislation of member states.

13. Firstly, the principle of anonymity of gamete donors raises a public health issue, since it means that the donor-conceived person cannot be informed of their genitor's medical history. Moreover, it increases the risk of consanguinity, as some donors who have made several donations may end up with several children, without the latter being able to know whether they are related when they wish to enter into a relationship with each other.<sup>18</sup> Despite the fact that some states limit the number of donations that can be made by a single donor, the "serial donors" phenomenon is exacerbated by the recurring lack of a system for exchanging information between clinics performing artificial insemination by donor within a state (for example, in my home country Belgium, or, historically, in the Netherlands<sup>19</sup>), and also by the phenomenon of cross-border donations.

14. Secondly, the principle of anonymity raises the fundamental ethical issue of the position of the donor-conceived person. Although the quest to find out about their identity by persons born as a result of anonymous gamete donation differs somewhat from that of adopted persons and may apparently seem "of lesser importance", it is nonetheless just as legitimate, as transpires from the claims of the many associations such as *Procréation Médicalement Anonyme*. Many donor-conceived persons believe that access to their donor's identity is a fundamental aspect of their identity building (as children and adults), although there are some donor-conceived persons who believe that assuring emotional and physical security to a child is more important than transmitting genetic material, and thus are interested only in the disclosure of non-identifying information.

15. The principle of anonymity of gamete donors is often modelled on the anonymous nature of organ donations, but it has different implications. Organ donations save lives whereas gamete donations create lives. The donation of gametes will therefore determine certain physical characteristics of the donor-conceived person. I thus believe that access to the donor's identity is a fundamental aspect of the child's identity building. However, for a donor-conceived child to be able to build its identity, it is, first of all, necessary for the child to be informed that he/she was conceived of gamete donation, which is far from being the norm, even today.<sup>20</sup>

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<sup>16</sup> Indeed, it is only relatively recently that a decision by the French *Conseil d'État* (12 November 2015, No. 372121, "Ms B...") rejected an application by a person conceived through gamete donation to obtain more information on their genitor in the interests of protecting the "life of the child's legal family" and the "donor's private life." In France, the principles of "free" and "anonymous" donation are enshrined in law, along the same lines as for blood donation, notwithstanding the donor's consent (Law No. 94-654 of 29 July 1994 on the donation and use of elements and products of the human body, on medically-assisted reproduction and on prenatal diagnosis).

<sup>17</sup> For further information on the interpretation of the European Court of Human Rights, please refer to: Brigitte Clark, *A Balancing Act?* Op. cit., pp. 630-633.

<sup>18</sup> However, a point made during the hearing was that the number of donor-conceived children is still smaller than the number of children who have been born of adultery.

<sup>19</sup> In the Netherlands, there are at least two donors who are suspected of having fathered up to 200 children each. See: 'I thought – who will remember me?': the man who fathered 200 children, published in the Guardian on 24 November 2018: [https://www.theguardian.com/science/2018/nov/24/sperm-donor-man-who-fathered-200-children?CMP=Share\\_iOSApp\\_Other](https://www.theguardian.com/science/2018/nov/24/sperm-donor-man-who-fathered-200-children?CMP=Share_iOSApp_Other)

<sup>20</sup> There are different schools of thought and different anecdotal evidence when it comes to when is the best time to tell a child that he/she is donor-conceived. Probably, as with adoptions, early and loving disclosure is in the best interest of the child, though any disclosure can be traumatising for a child – but none more so than accidental discovery.

16. An American study carried out in 2017 noted that in a sample of young American adults conceived through a sperm donation programme with the identity of the donor being accessible, 40% asked for access to the identity of the donor.<sup>21</sup> Another American study conducted in 2010 showed that 65% of donor-conceived persons considered that the donor constituted half of themselves, that 70% of them wondered what the family of their donor was like and 69% wondered if the donor's family would like to get to know them.<sup>22</sup> It can therefore reasonably be assumed that at least one out of two donor-conceived persons is seeking to know their origins, hence the importance for these persons of having access to certain information about their genitors. So-called "genealogical bewilderment" and a "fractured sense of identity" can lead to considerable suffering for donor-conceived persons who cannot access identifying information about their donors.<sup>23</sup> It is interesting to note in this regard that the parliamentary Victorian Law Reform Committee (Australia) in its 2012 inquiry report recognised that "donor-conceived people are *actually* suffering from their lack of knowledge about donors".<sup>24</sup>

17. Finally, the principle of anonymity is becoming obsolete due to the evolution of genetic technology, making it possible for a person to have access to their genetic data and therefore to find their genitor. "Recreational" genetic tests are becoming increasingly common world-wide and access to testing, whether via internet or when travelling abroad, is now very easy.<sup>25</sup> Donor anonymity is, *de facto*, no longer guaranteed today. It would therefore appear more appropriate to prevent potential excesses arising from developments in these technologies by waiving the anonymity of gamete donors and by managing the manner in which this information is communicated to the donor-conceived person, instead of allowing anonymity to remain in place although it has now become out-dated.

#### 4. Arguments in favour of waiving anonymity in order to better protect donor-conceived persons

18. It should first be said that the aim is not to abolish the anonymity requirement completely, but simply to waive it so that the parents cannot know the identity of the donor at the moment of insemination and vice versa, but the donor-conceived person can later have access to certain information. It is therefore more accurate to talk in terms of access to information rather than abolition of the principle of the anonymity of gamete donation. However, there would seem to be certain practical, as well as ethical, obstacles to such a waiver of the anonymity requirement.

19. The argument systematically put forward by the clinics which carry out artificial inseminations with donor sperm is that the number of donors will decrease in the event of a waiver of anonymity. However, this argument is not backed by statistics. No decrease in donations has been noted in the countries which have granted the right to have access to one's origins. In Sweden, for example, the 1984 law providing for the right of donor-conceived persons to have access to their genetic origins resulted in a decrease in the number of donors in the first year only, but this trend has now reversed.<sup>26</sup> In the United Kingdom since 2005, when

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<sup>21</sup> Scheib, J. (2017, 02). Who requests their sperm donor's identity? The first ten years of information releases to adults with open-identity donors. *Fertil Steril*. Available on : [https://www.fertstert.org/article/S0015-0282\(16\)62946-1/fulltext](https://www.fertstert.org/article/S0015-0282(16)62946-1/fulltext)

<sup>22</sup> Karen Clark, Norval Glenn and Elizabeth Marquardt, (2010, 01). My Daddy's Name is Donor: A Pathbreaking New Study of Young Adults Conceived Through Sperm Donation. Available on: <http://www.americanvalues.org/search/item.php?id=25>

<sup>23</sup> See Sonia Allan's guest editorial, op. cit., pp. 636-637, and Michelle Taylor-Sands, Removing donor anonymity: What does it achieve? Revisiting the welfare of donor-conceived individuals, 2018, pp. 9-11, <http://classic.austlii.edu.au/au/journals/UNSWLawJl/2018/19.html>.

<sup>24</sup> Cited in Sonia Allan's guest editorial, op. cit., p. 647 – full citation: "While the release of identifying information to donor-conceived people may potentially cause discomfort and distress to donors (although this will not always be the case), it is certain that donor-conceived people are actually suffering from their lack of knowledge about donors. Although debates about the consequences of releasing identifying information often focus on the suffering that donors may experience, the fact is that many donor-conceived people are already suffering, in some cases quite profoundly, from not having access to this information."

<sup>25</sup> In the United States, many donor-conceived persons have already identified their donor thanks to associations such as the Donor Sibling Registry, which has, alone, already helped more than 15 000 persons conceived by means of sperm donation find their donors or half-brothers and sisters (<https://donorsiblingregistry.com/>)

<sup>26</sup> Daniels, K. et Lalos, O. (1995) The Swedish Insemination Act and the availability of donors. *Hum. Reprod.* , 7, 1871–4.

the law changed, donations have steadily increased.<sup>27</sup> The different studies carried out have shown a substantial change in the donor profile, as they are generally older and have had time to think about their decision, but not a reduction in their number.

20. Lastly, an ethical obstacle is often cited by those opposed to recognition of the right of donor-conceived persons to have access to information on their genitors: the risk of eroding the family unit comprising the legal parents and the donor-conceived person in favour of the donor - the biological parent - and therefore of "reducing" filiation to biological parenthood. However, it is generally recognised that donor-conceived persons wishing to know their genetic origins already have parents and are not in pursuit of an emotional bond or looking for a family, but are instead searching for a part of their history and identity. Therefore, in view of changes in society and in attitudes with regard to the plurality of family types which can be noted today, it would seem easy to imagine a form of peaceful coexistence of the truth about a person's origins and their legal filiation, without the latter being under threat, as they clearly have different functions and prerogatives.<sup>28</sup>

21. Furthermore, in the countries where the right of access to one's origins has been recognised, waiving anonymity has had no legal consequences for filiation, as it is already established between the donor-conceived person and the legal parent.<sup>29</sup> The donor is thus protected from any request to determine parentage or an inheritance or parenting claim. The state and its bodies will have an essential role to play in this development, both with a view to eliminating the legal risks for filiation through legislation as well as to identify the donors and those who receive gamete donations in order to improve the transparency of AID techniques.

## 5. Balancing all interests

22. I believe it is useful to clarify once more who has which interests when it comes to gamete donation. I have identified the following interested parties: the legal parent(s), the donor(s), the donor-conceived person (as a child and as an adult), the clinics and service providers, and society (the State).

23. The legal parent(s) are the ones who seek to found a family with the help of ART, sperm and/or oocyte donation. Without their wish for a child, no donor-conceived child would be born - in contrast to adopted children or children abandoned at birth. The legal parents have the intention, right and obligation to parent the child conceived through gamete donation, which has led legislators and courts across countries to ensure that their legal parental filiation is not challenged by the donor(s). However, I am not aware of a jurisdiction which obliges the legal parents to inform their child that he/she is donor-conceived. Yet I doubt whether it is really in the interest of the legal parents to preserve "family peace" by hiding the method of conception from their child, as chances are that the child will find out at some point in any case. "Late" or accidental disclosure may lead to a child feeling betrayed by the legal parent(s), and may thus lead to estrangement rather than "family peace", which is not in the interest of the legal parents.<sup>30</sup> However, in some cultures (including in Europe) the use of ART continues to be viewed negatively (though the stigma seems to be decreasing), which can explain the reluctance of some parents to disclose.

24. What are the interests of the donor? In accordance with Council of Europe standards, gamete donation is meant to be a "voluntary and altruistic gesture with the sole aim of helping others,"<sup>31</sup> and thus

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<sup>27</sup> Human Fertilisation and Embryology Authority, (2014, 10). Egg and sperm donation in the UK: 2012-2013. *HFEA Archive*. Available on <://hfearchive.uksouth.cloudapp.azure.com/www.hfea.gov.uk/9370.html>

<sup>28</sup> For a differing view, see Brigitte Clark, *A Balancing Act?* Op. cit., pp. 639-648.

<sup>29</sup> There are exceptions: for example, see the rules on retrospective parentage in Ireland, well explained in an information booklet on Donor-Assisted Human Reproduction (DAHR) and the Law in Ireland published by the University of Limerick in its series UL ENGAGE Community Briefing (2017 no. 13). There are also some open questions as to Scottish law.

<sup>30</sup> The Nuffield Council on Bioethics, in its 2013 report on Donor conception: ethical aspects of information sharing, cited longitudinal studies of systematic samples of families which indicate that both 'disclosing' and 'non-disclosing' families function well up to early adolescence, but admitted that little is known about the functioning of families in later adolescence and adulthood, and that children who learn that they are donor-conceived when they are very young appear to assimilate this information without difficulty, while some adults who found out later in life have reacted negatively. See p. xviii and Chapter 4 on Knowledge of donor conception and access to donor information.

<sup>31</sup> See, for example, the EDQM publication "Donation of oocytes - A guide for women to support informed decisions", available for download on the department's website, 2018, as well as Article 21 of the Oviedo Convention on the prohibition of financial gain which is legally binding, and the Guide on prohibition of financial gain which is its implementation tool.

without any financial gain or comparable advantage for the donor. However, this does not prevent the reimbursement of justifiable expenses related to the donation itself (for example, travel, medication) or compensation for loss of earnings. Some donors have admitted having other motivations than the “sole aim of helping others”: reimbursement of such expenses can be quite high, in particular for cross-border oocyte donations, so sometimes there has been a financial motive; others have given psychological reasons, such as a wish for immortality. In most cases, it is in the interest of the donor to be protected from legal, financial or parenting claims. However, some donors – in particular later in life, and if they have founded no family of their own – welcome contact with the children/adults conceived by the donation and are interested in building a relationship with them (which can go as far as legal filiation in isolated cases). It is in general not in the interest of the donor for his/her identity to be revealed without his/her consent in situations when anonymity was promised at the time of the donation.

25. As already described above, donor-conceived children have not just an interest, but also a right to know their parents as far as possible; as adults, they retain the right to know their origins and the circumstances of their birth. For medical reasons and to avoid consanguinity, it is in their interest to have access at least to non-identifying information about their donor(s), but for their identity-building and personal development, having access to identifying information is usually also in their interest.<sup>32</sup> However, whether to exercise their possibility to access this information should be left to the discretion of the donor-conceived persons themselves in my view.<sup>33</sup> On another note, I believe it is not in the interest of donor-conceived persons to have far more half-siblings than is the norm.

26. The clinics and service-providers have an interest to be able to offer comprehensive ART services in compliance with the law, and an interest to keep accurate records whatever the legal situation in the country concerned in order to be able to comply with that legislation (including when it is changed retrospectively). Cross-border gamete donations and ART should be particularly meticulously documented.

27. Society – and thus the State – has an interest in ensuring individual and public health, and thus in ensuring an adequate legal and regulatory framework is in place which can, as a minimum, trace donors if the medical need should arise (for a transplant, for example), and has all the information recorded in a way that ensures that close blood relations cannot marry. The State also has the obligation to uphold and safeguard the fundamental rights of its citizens more generally, including the rights of all stakeholders as mentioned in these paragraphs, and an interest in keeping “social peace.”

28. Balancing all the above interests is not easy, and different solutions have been found in different countries at different times. One size may not fit all. However, it is also clear that some solutions have been better at avoiding abuses and at keeping the “social peace” than others. It should not be forgotten that donor-conceived persons risk losing their lives if their donor cannot or will not be identified (when they are in need of a transplant, for example), and that both some donors and some donor-conceived people have suffered greatly from accidental disclosure (including situations of consanguinity).

## 6. Conclusions and recommendations

29. The distinguishing features of the Council of Europe, namely its mandate encompassing the promotion of human rights, democracy and the rule of law, and its role of promoting good practice among the member states, place the Organisation in an ideal position to address the risks and challenges related to the anonymity of gamete donations.<sup>34</sup> It is thus for the Council of Europe to make recommendations to states in order to improve the protection of the rights of all the parties concerned, i.e., the parents, the donors and the children, while focusing on the rights of the donor-conceived person, who is in the most vulnerable position and for whom the stakes appear to be higher.

30. My recommendation would thus be, for all future gamete donations in Europe, to waive anonymity. This would mean that (except in exceptional cases, when the donation is from a close relative or friend), the

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<sup>32</sup> One can think of rare situations where accessing identifying information may not be in the interest of the donor-conceived persons, for example, in cases where the donor has committed serious crimes. This possibility is foreseen in the 2015 Law in Ireland – see the UL ENGAGE Community Briefing, op. cit., pp. 25-26. It should, however, be pointed out that the National Donor Conceived Person Register does not yet seem to have been set up, see: Brian Tobin, Donor-conceived children: It's time to ban anonymous donation, the journal.ie, 26 June 2018.

<sup>33</sup> Whether there may also be a right « not to know » that one is donor-conceived is, in my opinion, not so clear – and, in any case, made obsolete by advances in genetic testing.

<sup>34</sup> N.B.: The EU is not competent to regulate donor conception (the competence lies with member States).

donor's identity would not be revealed at the time of the donation, but upon the child's 16<sup>th</sup> or 18<sup>th</sup> birthday,<sup>35</sup> the donor-conceived child would be informed (ideally by the State) that there is supplementary information available on the circumstances of his/her birth. It would be up to the donor-conceived person whether and when to access this information containing the identity of the donor. The legal situation of the donor – no parental rights or responsibilities – would not change in this scenario.<sup>36</sup>

31. In this scenario, it would be up to the clinics to inform the State upon the birth of a donor-conceived child of the child's and the donor's identity, and up to the State to keep an up-to-date register of all donor-conceived children and their donors. There should also be an upper limit on the number of possible donations by the same donor which would need to be properly enforced.

32. Regarding donations made in the past where anonymity was promised, I don't believe this should be lifted retroactively, except for medical reasons or where the donor has consented to the lifting of the anonymity.<sup>37</sup> No changes to legal parentage should result from the lifting of the anonymity even when the donor has agreed to it being lifted. Donors should be offered counselling before they decide whether or not to agree to lift anonymity. Proper guidance, counselling and support should also be offered to donor-conceived persons before they decide whether to exercise their right to access information containing the identity of the donor.

33. These principles should be applied without prejudice to the overriding consideration that gamete donation must remain a voluntary and altruistic gesture with the sole aim of helping others, and thus without any financial gain or comparable advantage for the donor. I would suggest leaving it to the Committee of Ministers to decide whether these recommendations should ultimately become legally binding.

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<sup>35</sup> Most countries which have a legal framework permitting the waiving of anonymity have chosen the donor-conceived child's 18<sup>th</sup> birthday, but there is evidence – particularly from the international adoption field – that permitting a child access earlier helps the child's identity-building.

<sup>36</sup> My proposals in this regard are closely linked to the law in Ireland as changed in 2015, see the information booklet on Donor-Assisted Human Reproduction (DAHR) and the Law in Ireland published by the University of Limerick in its series UL ENGAGE Community Briefing, *op. cit.*

<sup>37</sup> The only jurisdiction I am aware of which has lifted anonymity retrospectively in all cases is the state of Victoria in Australia.