# Zero or 18: At Which Age Should UK's Fertility Watchdog Disclose Egg Donor Identity to Donor-Conceived Children?

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### INTRODUCTION

2023 will mark a major change to the UK's egg donor anonymity laws. Under rules in place since 2005, any child conceived using donated eggs, sperm or embryos and born after April 1, 2005 will be able to find out who their biological parents are when they turn 18, which occurs this year. At age 16, these children could access non-identifiable information about the donor, such as physical description or ethnicity.<sup>1</sup> However, just last May, the UK fertility watchdog Human Fertilisation and Embryology Authority (HFEA) proposed scrapping anonymity for future sperm and egg donors. Peter Thompson, the chief executive of the HFEA, said the rapid rise of direct-to-consumer (DTC) genetic testing websites, such as 23andMe and AncestryDNA, could soon make it impossible to guarantee donor anonymity – and that the law needs to reflect this reality.<sup>2</sup> Although the HFEA has not settled on a proposal around anonymity, one option under consideration is the HFEA lifting the anonymity of donors at birth rather than when the donor-conceived individual reaches age 18.

## ANALYSIS

The issue of if the HFEA should disclose donor identity before the donor-conceived children reach 18 raises many ethical questions. It is important to consider the potential impact of such a decision on all parties involved, including the child, the donor, and the recipient parents.

Identity-release egg donation has been the only treatment option available to patients wishing to pursue this route to parenthood in the UK since 2005. This means that the donor is anonymous to the intended parents at the time of treatment, but the child has the right to access identifying information about the donor at the age of 18. Despite strict HFEA laws protecting the identity of donors until then, the HFEA cannot guarantee donor anonymity anymore. In the age of ancestry websites, genetic disease screening,

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and sibling registries, donor-conceived offspring can order an inexpensive saliva DNA test and identify genetic relatives from worldwide genetic databases, as for example by using "relative finder" in 23andme.<sup>3</sup>

Other tools exist to penetrate anonymity, including facial recognition software when agencies provide donor photos to recipient parents.<sup>4</sup> One's identity could be inferred by combining genetic information with other publicly available information, such as posts on social media.<sup>5</sup> As a result, current HFEA laws can no longer safely protect donor anonymity.<sup>6</sup>

Children's rights to know their biological origins are outlined in the United Nations Convention on the Rights of the Child under Article 3 (putting the best interests of the child as the primary consideration) and Article 7 (the right to birth registration) of the United Nations Convention on the Rights of the Child.<sup>7</sup> The UN Committee on the Rights of the Child has criticized the UK legal system for withholding such information from children born by donor conception.<sup>8</sup> Disclosing the donor's identity to the child at birth could be seen as a way to provide the child with a complete sense of identity and to give them the opportunity to establish a relationship with the donor and potentially their biological siblings from an early age. The child can also understand their genetic background and medical history. Louise McLoughlin, a 30-year-old London based journalist, believes the HFEA should revise the laws revealing donor identity to the offspring at 18 as current regulations feel "arbitrary and cruel."<sup>9</sup> McLoughlin, who found her half-sister and biological father after signing up for 23andMe, regrets not being able to know her family sooner. "The fertility industry is creating people, not children, and we have the right to know any and all genetic history,"<sup>10</sup> she said in an interview with *The Guardian*.

Others feel differently. In a study conducted with adolescents conceived using egg donation, some participants expressed concern that their interest in the donor might affect their non-genetic parent. One participant stated that she'd contact her donor only when she became 50 or 60 because her "mum might be a bit upset."<sup>11</sup> Others, like Chlöe Woodmansternem, who was donor-conceived in 1992 when anonymity laws were still in place, have no desire to find her donor or any half-siblings. She questions the need for changes to the law. "I wonder if it wouldn't be a little confusing for a younger child to have access to that information," she said. "To have access to a donor, to be able to almost leverage that relationship against your own parents, could be a bit difficult."<sup>12</sup>

There is also the issue of which aspects of donor information a child should have access to and at what age. At birth, the child should have access to medical information about the donor, including any genetic or hereditary conditions, as children can take actionable steps towards prevention or early detection of certain disorders. The child should also have access to non-identifying information, such as the donor's age, ethnicity, physical description, interests, educational background, and occupation, as it can help the child understand their genetic heritage and provide a sense of identity. Gamete recipient families benefit from open communication about the child's genetic origins.<sup>13</sup> The earlier children are informed, the better the outcome in terms of their emotional and identity development.<sup>14</sup> In the UK, clinics and regulatory bodies encourage parents to begin telling their children about their method of conception around the age of four or five. However, it is unclear at what age children should have access to the donor's identifying information or when parents should inform children about their right to do so. Based on research, most children have an implicit understanding of biological inheritance of physical characteristics by age four, but they are not able to explain this concept and understand the role of genetic mechanisms until age seven.<sup>15</sup> This leads to the question of when children would develop the emotional maturity to handle the consequences of this information.

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Repealing anonymity at birth could put the egg donor's privacy at risk. 18-year-olds who decide to contact their donors may be more mature than younger people conceived by donor eggs. They may have the capacity to consider whether they wish to disclose the donors' identity to family members or others significant to them, or to honor the donors' desire for a certain degree of anonymity. On the other hand, younger children may be less likely to fully comprehend the importance of confidentiality and could unintentionally reveal details about their donor without fully grasping the implications. If younger children divulge donor information on social media platforms, it could compromise the donor's privacy and erode the donor's trust in the child. The family members of the donor or the recipient may not have been aware of the donor's involvement in the egg donation process. Egg donation is still a controversial and sometimes stigmatized practice in some cultures, and either party could be harassed or discriminated against based on their decision. Additional factors to consider are whether the child is emotionally ready to initiate contact with the donor and how they would handle maintaining an ongoing relationship, acknowledging that not all donors may be open to communication or may be unavailable due to illness or death, considering how to proceed if family members oppose the child's desire to contact the donor, and taking into account the potential effects on the parents' psychological well-being.

Allowing the child access to the donor's identity at an early age may also negatively influence family functioning as non-genetic mothers may perceive donors as an ongoing presence within the family, thus posing a threat to the mother-child relationship.<sup>16</sup> While some recipient mothers feel confident in their position as the child's mother and in their relationship with the child, others express concerns that a known donor could pose a threat to their maternal identity by the donor potentially feeling they have "a stake in [the child]'s upbringing" and by interfering in their parenting by "looking at you or disapproving of the way you were bringing up the child."<sup>17</sup> These concerns may affect parents' sense of entitlement and confidence in their position as the child's parents and the future security of their family unit but may be particularly salient for mothers.<sup>18</sup>

#### CONCLUSION

Removing egg donor anonymity laws at birth can have both positive and negative impacts on donor children's wellbeing. It would allow them to have more autonomy in deciding whether to establish a relationship with the donor. Yet, some children may find the information overwhelming or distressing, particularly if it affects their sense of identity, self-esteem, and relationships. The proposed new law would allow the donor to meet the child when they are still growing up but leaves them vulnerable to losing anonymity and confidentiality at an earlier stage. Finally, the potential for the child to obtain the identity of the egg donor at an early age may put pressure on the parent-child relationship due to the absence of a genetic link between the mother and the child. Regardless of which stage an egg donor would be identifiable to the child, it is essential that support services be available to the child, the egg donor, and the recipient parents. It may also be beneficial to allow for a diversity of donor conception arrangements, rather than imposing one model on everyone, as different individuals have varying preferences and perspectives.<sup>19</sup> Any proposed change to the law needs to be very carefully thought through, with the involvement of all stakeholders.

<sup>&</sup>lt;sup>1</sup> Human Fertilisation and Embryology Authority. Rules around releasing donor information. (2022, November 3). Retrieved February 19, 2023, from <u>https://www.hfea.gov.uk/donation/donors/rules-around-releasing-donor-information/</u>

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<sup>4</sup> Woodward, J. T. (2015). Third-party reproduction in the internet age: The new, patient-centered landscape. Fertility and Sterility, 104(3), 525–530. <u>https://doi.org/10.1016/j.fertnstert.2015.05.030</u>

<sup>5</sup> Human Fertilisation and Embryology Authority. Rules around releasing donor information. (2022)

<sup>6</sup> Pasch, L. A. (2018). New realities for the practice of egg donation: A family-building perspective. Fertility and Sterility, 110(7), 1194–1202. <u>https://doi.org/10.1016/j.fertnstert.2018.08.055</u>

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<sup>9</sup> Devlin. UK fertility watchdog could recommend scrapping Donor Anonymity Law. (2022)

<sup>10</sup> Devlin. UK fertility watchdog could recommend scrapping Donor Anonymity Law. (2022)

<sup>11</sup>Zadeh S, Ilioi EC, Jadva V, Golombok S. The perspectives of adolescents conceived using surrogacy, egg or sperm donation. Hum Reprod. 2018 Jun 1;33(6):1099-1106. doi: 10.1093/humrep/dey088. PMID: 29701833; PMCID: PMC5972639.

<sup>12</sup> Devlin, "UK fertility watchdog"

<sup>13</sup> Gurtin, Z. (2023, January 3). At last, Britain's donor-conceived children can know the truth about their origins. The Guardian. Retrieved February 19, 2023, from <u>https://www.theguardian.com/commentisfree/2023/jan/03/children-donor-conceived-origins-sperm-egg-donations</u>

<sup>14</sup> Hershberger, P. E., Gallo, A. M., Adlam, K., Driessnack, M., Grotevant, H. D., Klock, S. C., Pasch, L., & amp; Gruss, V. (2021). Parents' experiences telling children conceived by gamete and embryo donation about their genetic origins. F&S Reports, 2(4), 479–486. <u>https://doi.org/10.1016/j.xfre.2021.08.002</u>

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<sup>18</sup> Imrie, Jadva, Fishel & Golombok, "Families created by Egg Donation: Parent-child relationship quality in infancy", 1333–1349.

<sup>19</sup> Devlin, "UK fertility watchdog"