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Title: Mitochondrial Donations and the Right to Know and Trace One's Genetic Origins: an Ethical and Legal Challenge

Keywords:
Three-parent IVF, three-person embryos, mitochondrial donations, right to know

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Abstract:
The UK was the first country to legalize in 2015 the mitochondrial donation and replacement procedure, which allows the three-parent *in vitro* fertilization, and results in three-parent embryos. In March 2017, the UK Human Fertilisation and Embryology Authority issued its first license for the mitochondrial donation and replacement procedure to the Newcastle Fertility Centre. This paper discusses the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572, and then it focuses its discussion on one fundamental ethical and a legal challenge that this legislation overlooks: the right of the conceived children to know and trace their genetic origins. The paper argues that this is a natural and basic human right, which is guaranteed by legal documents in the UK and internationally, and is also morally justified. The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 discriminate against three-parent persons by negating their right to know and trace their genetic origins. The paper concludes with a justification for the specific amendment of the Regulations so to remedy the said unjust discrimination and violation of the natural and basic right to know and trace their genetic origins.

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Introduction

The UK was the first country to legalize in 2015 the mitochondrial donation procedure, which allows the three-parent *in vitro* fertilization, and results in three-parent embryos. In March 2017, the UK Human Fertilisation and Embryology Authority issued its first license for the mitochondrial donation procedure to the Newcastle Fertility Centre. The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 legalized two types of mitochondrial replacement techniques, namely the maternal spindle transfer – MST, and the pronuclear transfer – PNT[1]. The purpose of the Regulations is 'to prevent the transmission of serious mitochondrial disease from a mother to her child'[2]. Some examples of these genetic diseases caused by mitochondrial mutations are muscular dystrophy, liver diseases, and acute respiratory problems[3]. These severe mitochondrial diseases are passed from mother to their offspring through the mitochondria in the cytoplasm of a mother's ovum. The purpose of both techniques (i.e., MST and PNT) is to prevent these diseases by replacing faulty mitochondria from the mother by a healthy one from another woman (i.e., the donor).[4]

Both MST and PNT are similar techniques. The main difference is that MST uses two eggs (one from the mother and one from the donor), and the unhealthy mitochondria from the mother's egg are removed and replaced by the healthy mitochondria from the donor's egg. [5] In the PNT technique,

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[1] J A Scully, '*A Mitochondrial Story: Mitochondrial replacement, identity and narrative*', (2017) Bioethics, vol 31(1), 37; L Craven, H A Tuppen, G D Greggains, et al., '*Pronuclear transfer in human embryos to prevent transmission of mitochondrial DNA disease',* (2010) Nature, vol 465, 82; M Tachibana, M Sparman, H Sritanaudomchai, et al., '*Mitochondrial gene replacement in primate offspring and embryonic stem cells*', (2010) Nature, vol 461, 367.

[2] Department of Health, '*Mitochondrial Donation, Government response to the consultation on draft regulations to permit the use of new treatment techniques to prevent the transmission of a serious mitochondrial disease from mother to child*', (2014), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/332881/Consultation_response.pdf [Accessed 10 June 2017].

[3] S. Di Mauro, '*A history of mitochondrial diseases*', (2011) J Inherit Metab Dis, vol 34, 261.

[4] M Scarpelli, A Todeschini , I Volonghi , A Padovani, M Filosto*,'Mitochondrial diseases: advances and issues*, (2017)The Application of Clinical Genetics, vol 10, 21; S DiMauro, '*Mitochondrial encephalomyopathies—fifty years on: the Robert Wartenberg Lecture*', (2013) *Neurolog*y, vol 81, 281; E A Schon, S DiMauro, M Hirano, '*Human mitochondrial DNA: roles of inherited and somatic mutations',* (2012) *Nat Rev Genet* (2012), 13, 878; E C Spikings, J Alderson, and JCS John JCS, '*Transmission of mitochondrial DNA following assisted reproduction and nuclear transfer',* (2006) *Human Reproduction Updat*e, vol 12, 401; D C Wallace, G Singh, M T Lott, *et al., 'Mitochondrial DNA mutation associated with Leber's hereditary optic neuropathy'*, (1988) *Science*, vol 9, 1427.

S G Pavlakis, P C Phillips, S DiMauro, D C De Vivo, L P Rowland, '*Mitochondrial myopathy, encephalopathy, lactic acidosis, and strokelike episodes: a distinctive clinical syndrome',* (1984) *Ann Neurol*, vol 16(4), 481;

L P Rowland, A P Hays, S DiMauro, D C De Vivo, M Behrens, '*Diverse clinical disorders associated with morphological abnormalities of mitochondria',* C. Cerri, G. Scarlato (Eds.), in *Mitochondrial Pathology in Muscle Diseases*, (Piccin Editore, Padua, 1983)141.

[5] The research on MST showed that 'the mitochondrial genome can be efficiently replaced in mature non-human primate oocytes (Macaca mulatta) by spindle-chromosomal complex transfer from one egg to an enucleated, mitochondrial-replete egg'. The research then concluded that to avoid recurrence of mtDNA mutations, 'the nuclear genetic material from a patient's egg containing mtDNA mutations could be removed, and transplanted into an enucleated egg containing normal mtDNA donated by a healthy female. A child born after fertilization with the partner's sperm would be free of risk

two embryos, rather than two eggs, are used. [6] The first embryo is the result of the union between the mother's egg and the father's sperm. The second embryo is the result of the union of the donor's egg and the father's sperm. The unhealthy mitochondria of the first embryo are then removed and replaced by the healthy mitochondria of the second embryo. As the Nuffield Council on Bioethics puts it: 'MST is a transfer technique that works on a similar principle to PNT. The main difference between the two techniques is that MST uses two unfertilised eggs to reconstruct an egg with healthy mitochondria that can then be fertilised; in PNT, two early embryos (zygotes) are used to reconstruct an embryo with healthy mitochondria'. [7]

Studies concluded that both techniques are successful in preventing the transmission of severe mitochondrial disease from mother to child, and studies also found that the conceived child carries minimal mitochondrial DNA (mtDNA) from her egg donor. Researchers claim that 'the average level of carry-over after transfer of two pronuclei is less than 2.0%, with many of the embryos containing no detectable donor mtDNA[8]. Purportedly this negligible percentage is the reason why the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 do not recognize the egg donor as a parent, and why the Regulations do not safeguard the right of the conceived child to know and trace her genetic origins. Some support that in both techniques, the conceived embryos carry 'minimal' or 'no detectable' egg donor mtDNA.[9] Some others claim that although 2.0% may be 'minimal', 'no detactable', or insignificant quantitatively speaking, it is qualitatively essential: without these 2.0% level of carry-over after transfer of two pronuclei, the three-parent IVF technique would not exist, and the mitochondrial disease-free embryos would not exist either.[10] In this sense, the 2.0% level of carry-over is an essential part of both the technique and the conceived embryos.

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from maternal mtDNA mutations as well as being the biological child of the patients.' (M Tachibana, et al., '*Mitochondrial gene replacement in primate offspring and embryonic stem cells*', (2009) Nature, vol 461, 367).

[6] The research on PTN '*involved the transfer of one or two pronuclei between abnormally fertilized zygotes.*'

(L Craven, H A Tuppen, G D Greggains, et al., '*Pronuclear transfer in human embryos to prevent transmission of mitochondrial DNA disease*', (2010) Nature, vol 465, 83).

[7] Nuffield Council on Bioethics, '*Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review*', (2012), 36, http://nuffieldbioethics.org/wp-content/uploads/2014/06/Novel_techniques_for_the_prevention_of_mitochondrial_DNA_disorders_compressed.pdf. [Accessed 8 June 2017].

[8] L Craven, H A Tuppen, G D Greggains, et al., '*Pronuclear transfer in human embryos to prevent transmission of mitochondrial DNA disease*', (2010) Nature, vol 465, 82.

[9] Sarah Barber, Peter Border, '*Mitochondrial Donation*', (29 January 2015), 22 <researchbriefings.files.parliament.uk/documents/SN06833/SN06833.pdf> [Accessed 5 July 2017]

L Craven, H A Tuppen, G D Greggains, et al., '*Pronuclear transfer in human embryos to prevent transmission of mitochondrial DNA disease*', (2010) Nature, vol 465, 82.

[10] The authors are grateful for Joseph Tham LC for this making point.

Also, some studies argue that it is more accurate to say that the conceived embryos have three parents because the embryos are the result of the father's sperm, the mother's egg, and the donor's egg.[11] Although the scientific community is divided on this matter, both sides would at least agree that each of these three individuals contributed something unique -- even if 'minimal' or 'no detectable' or insignificant quantitatively speaking -- to the conceived child. This is the common ground between the opposing sides. Certainly, they would disagree on the relevance and degree of such contributions, but they would nevertheless at least agree that were it not for these three particular individuals, this particular embryo, with these particular characteristics, would not exist. Based on this common ground (i.e., the fact that these three individuals contributed something unique to the conceived child), the paper will argue below that these three particular individuals are genetically/biologically linked -- even if to a 'minimal' or 'no detectable' degree -- to the conceived child, and therefore can qualify as genetic/biological parents of said child.

The legalization of MST and PNT techniques is still very controversial, as it raises some vexed ethical questions, related, for example, to: (i) the risks and potential harms involved in germline genetic manipulation;[12] (ii) the creation, testing, and destruction of embryos solely to enable another embryo to be made mitochondrial disease-free;[13] (iii) the typical slippery slope argument, which here would

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[11] Reuven Brandt, '*Mitochondrial donation and "the right to know"*', (2016) Journal of Medical Ethics, vol 42, 678.

D A Jones, '*The other woman: evaluating the language of 'three-parent' embryos*', (2015) Clinical Ethics, vol 10(4), 97, 101.

[12] The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 allow UK scientists to alter the genome of the conceived child. In other words, the Regulations allow the alteration of the human germline (i.e., the genes that pass on to future generations). These genetic modifications in the conceived child are contentious because they are irreversible, and are transmitted throughout her hereditary line. (Edward Lanphier, Fyodor Urnov, Sarah Ehlen Haecher, et al., '*Don't edit the Human Germ Line*', (2015) Nature, vol 519 (7544), 410)

The typical ethical concern that the alteration of the human germline raises relates to the risks and potential harms created in the course of germline genetic manipulation, both to the conceived child and to future generations. It has been argued that it is impossible to predict how the alteration of the germline will impact the future not only of the child but also of the human race in general. (Michael J Reiss, '*What Sort of People Do We Want? The Ethics of Changing People Through Genetic Engineering*', (1999) Notre Dame Journal of Law, Ethics and Public Policy, vol 63 (13), 80).

It is worth clarifying, however, that not all genetic alterations are passed down to future generations. For example, gene therapy on non-reproductive cells (somatic cells, such as muscle cells or neurons) repairs or replaces defective genes and do not pass down to future generations. Therefore, gene therapy on non-reproductive cells does not prima facie raise this kind of ethical objection, and as such can be prima facie morally justifiable.

As Sandel puts it: 'only germline genetic interventions, which target eggs, sperm, or embryos, affect subsequent generations' (See: M J Sandel, 'The case against perfection: Ethics in the age of genetic engineering', (2007) Belknap Press, 8)

[13] The ethical controversy on the creation, testing, and destruction of human embryos revolves around the vexed philosophical question of personhood (e.g., when a person begins to exist and what the moral status of the human embryo is). One's particular views on personhood aside, considering that a human embryo is a form of human life – meaning 'it is living rather than dead, and it is human rather than, say, bovine' (Sandel, 2007, 115), the creation, use, and destruction of any form of human life (e.g., human embryos) for the purpose of scientific innovation, even if such scientific innovation carries the good intention of enabling another embryo to be made mitochondrial disease-free, is

entail the question on the manufacturing of genetically modified 'ideal' children, commodification and eugenics,[14] and (iv) the right of the conceived children to know and trace their genetic origins.

To be sure, none of these four questions are exclusive to the context of mitochondrial donation. In actuality, all these topics have been extensively dealt with in other settings as well. For example, question #1 on the risks and potential harms involved in germline genetic manipulation has been recently discussed in the context of the CRISPR-Cas9 DNA editing technology. Protracted question #2 on the creation, testing, and destruction of embryos has been widely discussed in regards to IVF techniques in general and human embryo research (e.g., embryonic stem cell research) broadly considered. Question #3 on the manufacturing of genetically modified 'ideal' children, including discussions on commodification and eugenics, has been dealt with in the context of prenatal screening and prenatal genetic diagnosis. Question #4 on the right of the conceived children to know and trace their genetic origins has been brought up also in the contexts of adoption, naturally conceived-children with misattributed paternity, and Assisted Reproductive Technologies – ARTs in general. This paper focuses only on question #4, applied to one particular ART, namely the three-parent IVF technique because it brings a specific and distinct ethical and legal challenge to the Regulations that legalized it in the UK.

To discuss this specific and distinct ethical and legal challenge to the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572, the paper first conceptualizes the right of the conceived children to know and trace their genetic origins. The paper will argue that it is a natural and basic human right, which is guaranteed by legal documents in the UK and internationally, and which is also morally justified. After discussing the right to know and trace their genetic origins (section 1), the paper then explains (section 2) why the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 discriminate against three-parent persons by negating their right to know and trace their genetic origins. The paper then concludes with a justification for a specific amendment of the Regulations so to remedy the said unjust discrimination and violation of the natural and basic right to know and trace their genetic origins.

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controversial because it involves the ethical issue of using human lives as means to something (in this case, scientific innovation), rather than respecting human lives as ends in themselves.

[14] Commodification is the transformation of human beings into commodities or objects of trade, and eugenics is the practice that aims at enhancing the genetic make-up of the human population. It has been argued that the Regulations raise questions of commodification and eugenics because the Regulations legalize the manufacturing of genetically modified 'ideal' children (the so-called 'designer babies' (See Aldous Huxley's 1932 novel *Brave New World*), or 'made-to-order children' (Sandel, 2007, 7). The argument that has been raised is this: if the Regulations allow genetic modifications to prevent mitochondrial diseases, it is likely that future regulations would allow other sorts genetic modifications to get rid of different sorts of unwanted features, as well as to create and enhance wanted attributes. This is the standard slippery slope argument.

1. Donor-Conceived children's right to know and trace their genetic origins

The right to know is an internationally recognized human right. It is enshrined by the 1989 United Nation Convention on the Rights of the Child (CRC) in its articles 7 and 8.[15] In the same year, the European Court of Human Rights further interpreted CRC's article 8 in Gaskin v UK [16], clarifying that access to information, which includes the identity of one's parents, is a pivotal aspect of one's identity. The right to know and trace one's own genetic origins is also enshrined in several jurisdictions across the globe, including Austria[17], Finland[18], Germany[19], Netherlands[20], New South Wales[21], New Zealand[22], Norway[23], Sweden[24], Victoria[25] and Western Australia[26].

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[15] Article 7(1), CRC: '[t]he child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the *right to know* and be cared for by his or her parents.'

Article 8, CRC: '1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference. 2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing his or her identity'

Freeman suggests that the term "parents" in Article 7 includes not only social or legal parents, but also biological or genetic parents. (M. Freeman, "The New Birth Right? Identity and the Child of the Reproductive Revolution" (1996) Int'l. J. Child. Rts. 273)

[16] Gaskin v UK [1989] 12 E.H.R.R. 36

[17] Reproductive Medicine Act 1992, s.20 (2).

[18] Act on Assisted Fertility Treatments 2006.

[19] The German Federal Constitutional Court held that all people have a constitutional right to obtain information about their genetic heritage. See: *Bundesverfassungsgericht*, 1 BvR Jan. 18, 1988, docket no. 1 BvR 1589/87.

[20] Assisted Insemination (Donor Data) Act 2002, art 3(2) paragraph 2.

[21] Assisted Reproductive Technology Act 2007, s.38(1)(c).

[22] Human Artificial Reproductive technology Act 2004, s.65.

[23] Act on Bioethecnology 2003.

[24] Genetic Integrity Act 2006, chapter 6.

[25] National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (Australian Government, 2007); Assisted Reproductive Treatment Act 2008, s. 59.

[26] Human Reproductive Technology Amendment Act 2004, s.33(3).

The right to know and trace one's own genetic origin[27] is defined as the right of donor-conceived persons to access information concerning the donors of their genetic material (e.g., sperm, eggs, embryos).[28] Despite its apparent straightforwardness, this right is broad enough to generate interpretative challenges at least on three aspects, namely (i) the medical aspect (i.e., the right to access one's full family medical history as well as other medically relevant genetic information about the donors); (ii) the identity aspect (i.e., the right to access personal information about the identity of the donors, which could assist the offspring in forming and completing the picture of his/her own identity)[29]; and (iii) the relational aspect (i.e., the right to know the full identity of the donors, including their exact location, with the purpose of attempting to establish a relationship with them)[30].

As mentioned before, although the right to know and trace one's genetic origins applies by and large in the contexts of adoption, naturally conceived-children with misattributed paternity, and Assisted Reproductive Technologies – ARTs in general, this paper focuses only on the latter. In the context of ARTs, the right to know and trace one's genetic origins gives the donor-conceived child the right to access some information about her sperm, egg, or embryo donor.

In the UK, the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004/1511 recognized the right to know and trace one's genetic origins as a legal right on 1 April 2005. This means that, in the UK, sperm, egg, or embryo donors are required to provide personal information and contact details that may be passed on to any potential donor-conceived individual.[31] Before 1 April 2005, the right to know and trace one's genetic origins was not a legal right in the UK, and therefore sperm, egg or embryo donation occurred anonymously.

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[27] For a different perspective that questions that the right to know actually contributes to the welfare of the child, see: J Fortin, (2009) 21 *CFLQ* 336-355; *Re J (Paternity: Welfare of Child)* [2007] 1 FLR 1064; A Bainham, (2007) 66 CLJ 278-282 at 281); *Re AB (Care Proceedings)* [2003] EWCA Civ 1842.

[28] M. Cowden, '*'No Harm, No Foul': A Child's Right to Know Their Genetic Parents*', (2012) International Journal of Law, Policy and the Famil*y*, vol 26, 102; Reuven Brandt, '*Mitochondrial donation and "the right to know"*', (2016) Journal of Medical Ethics, vol 42, 678; Guichon J, Giroux M, Mitchell I, editors. '*The Right to Know One's Origins: Assisted Human Reproduction and the Best Interests of Children*' (Brussels: ASP - Academic & Scientific Publishers, 2013); V Ravitsky, '*Knowing where you come from: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness',* (2010*)* Minn J Law Sci Technol., vol 11(2), 655; N. R. Cahn, 'T*est Tube Families: Why the Fertility Market Needs Legal Regulation' (*New York: New York University Press, 2009); J. D. Velleman, '*Family History*', (2005) *Philosophical Papers*, vol 34, 357.

[29] J Guichon, M Giroux, I Mitchell, editors,'*The Right to Know One's Origins: Assisted Human Reproduction and the Best Interests of Children*', (Brussels: ASP - Academic & Scientific Publishers, 2013).

[30] V Ravitsky, '*The right to know one's genetic origins and cross-border medically assisted reproduction*', (2017) Israel Journal of Health Policy Research, vol 6 (3),2.

[31] The donor-conceived individual cannot access this information until the individual reaches the age of majority (i.e., 18 years).

The Human Fertilisation and Embryology Authority Register of Information has a record of all ARTs-related births from licensed UK fertility clinics from 1 April 2005 onwards. Legal parents of a donor-conceived child can access specific information about their child's donor, including details of their year of birth for example. Disclosure of the circumstances of conception remains the prerogative of legal parents given that no information is recorded on the child's birth certificate to show that she was donor-conceived. However, the UK Human Fertilisation and Embryology Act enshrines the disclosure of such information by legal parents[32], since it is in the donor-conceived child's best interest to be aware of the circumstances of her conception, and learn about it in a gradual process that should ideally start from a very young age. However, as guardians of donor-conceived children's best interests, legal parents in the UK are given the authority to choose whether or not to disclose such information, as well as how and when to do so.

In the UK, by the age of 16 (or below that age, so long as the minor has her legal parents' support), a donor-conceived child has the legal right to access non-identifying information about her donor, and about any donor-conceived genetic siblings.[33] From age 18, a donor-conceived person has the legal right to access some other specific identifying information about her sperm, egg, or embryo donors, including the donor's name, date of birth, and last known address.[34] This technically gives the donor-conceived person the means to contact her donor if she wants, although in practice it might be more difficult to actually make contact since any contact details given at the time of donation would be at least 18 years old and would not allow for any subsequent change or update in the donor's name (e.g., the donor, subsequent to the donation, marries and changes his/her name, or the donor, subsequent to the donation, undergoes gender reassignment and changes his/her name).

Although in the UK and in various other countries (e.g., Austria[35], Finland[36], Germany[37],

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[32] Human Fertilisation and Embryology Act 2008 s14(3)(6C)(a) and (b).

[33] There is a partial disclosure of some general information concerning the donor (e.g., date, time and place of birth, health, and psychological history).

[34] The donor-conceived person has, therefore, the right to access specific information, which does permit her to identify her donors (e.g., name, date of birth, address).

[35] Reproductive Medicine Act 1992, s.20 (2).

[36] Act on Assisted Fertility Treatments 2006.

[37] The German Federal Constitutional Court held that all people have a constitutional right to obtain information about their genetic heritage. See: *Bundesverfassungsgericht,* 1 BvR Jan. 18, 1988, docket no. 1 BvR 1589/87.

Netherlands[38], New South Wales[39], New Zealand[40], Norway[41], Sweden[42], Victoria[43] and Western Australia[44]) the right to know and trace one's genetic origins has been recognized as a legal right, in a few other countries their laws still protect the anonymity of donors (e.g., Spain, France, Denmark).[45] Those who argue against the right to know and trace one's genetic origins and in favor of anonymity laws claim that this right does not necessarily guarantee more protection of the best interests of the donor-conceived person, compared to the protection presumably provided by anonymity laws. De Melo-Martin presents a forceful argument against the right to know and trace one's genetic origins, challenging all of its three aspects, namely the medical, the identity, and the relational aspects.

Regarding the medical aspect, De Melo-Martin questions whether having access to full family medical history and other medically relevant genetic information is necessary for the best interest of the donor-conceived person. Surely having accurate information about a family medical history is essential to guarantee the donor-conceived persons' health interests. She observes, however, that anonymity policies do not mandate non-disclosure of such information. Also, she points out that gamete donors usually undergo genetic screening and are routinely asked to provide information concerning their family medical history, which, she claims, guarantees the donor-conceived person's health interests. In this sense, for De Melo-Martin, anonymity needs not and does not impede the protection of the donor-conceived person's health interests.

Regarding the identity aspect, De Melo-Martin questions whether having access to personal information about the identity of the donors is necessarily beneficial to the formation of the donor-conceived person's own identity. Although she agrees that the formation of their own identity is obviously 'a vital human interest' of donor conceived persons, De Melo-Martin highlights that identity formation depends on a range of conditions (e.g., social factors, education) that go well beyond

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[38] Assisted Insemination (Donor Data) Act 2002, art 3(2) paragraph 2.

[39] Assisted Reproductive Technology Act 2007, s.38(1)(c).

[40] Human Artificial Reproductive technology Act 2004, s.65.

[41] Act on Bioethecnology 2003.

[42] Genetic Integrity Act 2006, chapter 6.

[43] National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (Australian Government, 2007); Assisted Reproductive Treatment Act 2008, s. 59.

[44] Human Reproductive Technology Amendment Act 2004, s.33(3).

[45] V Ravitsky, 2017, '*The right to know one's genetic origins and cross-border medically assisted reproduction'*, (2017), Israel Journal of Health Policy Research, vol 6 (3), 1.

genetic and biological conditions. There is no strong empirical evidence, she claims, showing that donor-conceived people suffer 'genealogical bewilderment'[46] for not having access to their donor's personal information. In this sense, she argues that depriving donor-conceived people of such information is not automatically wrong, and it might be in their best interest to withdraw this information from them. Also, she highlights that the right to know and trace one's genetic origins puts an excessive and thus unhealthy importance on the role of genetics and biology in the constitution of personal identity. As she puts it: 'emphasizing the importance of genetic information might have the effect of pathologizing individuals who lack access to information about their genetic parentage. It might also encourage problematic beliefs about the superiority of biological families'[47]. In this sense, an over-emphasis on genetic and biological ties might stigmatize donor-conceived people (as well as adopted children), rather than contributing to their well-being.

Regarding the relational aspect, De Melo-Martin questions whether attempting to establish a relationship with the donor necessarily strengthens the donor-conceived person's family ties. It is undeniable that donor-conceived persons (as any other person) have a keen interest in cultivating good family relations. However, De Melo-Martin argues that disclosing the donor-conceived person's mode of conception does not automatically entail stronger family relations. She points out that such disclosure has often caused disruption rather than the union in families. As she puts it: 'if disclosing the mode of conception in the context of anonymity seriously disrupts family relationships, then that fact might be an argument against disclosure rather than against anonymity policies'[48]

In challenging the three levels of the right to know and trace one's genetic origins (namely, the medical, the identity, and the relational aspects), De Melo-Martin argues against said right. In concluding that there is not enough empirical evidence supporting the benefits for the donor-conceived individual at the medical, identity, and relational levels, De Melo-Martin finds that there are not good justifications to ground said right.

Ravitsky[49] responds to De Melo-Martins' points, and provides a defense of the right to know and

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[46] I De Melo-Martin, '*The ethics of Anonymous Gamete Donation*', (March-April 2014) Hasting Cent Rep, 28,33.

[47] De Melo-Martin, (n 60).

[48] I De Melo-Martin, '*The ethics of Anonymous Gamete Donation*', (March-April 2014) Hasting Center Report, 28, 30.

[49] V Ravitsky, '*The right to know one's genetic origins and cross-border medically assisted reproduction*', (2017) Israel Journal of Health Policy Researc*h*, vol 6 (3), 1; V Ravitsky, '*Donor conception and lack of access to genetic heritage',* (2016*)* Am J Bioethics, vol 16(12), 45; V Ravitsky, 'A*utonomous Choice and the Right to Know One's Genetic Origins',* (2014*)* Hastings Cent Rep, vol 44(2), 36; V Ravitsky, '*Conceived and Deceived: The Medical Interests of Donor-Conceived Individuals*', (2012) *Hastings Cent Rep*., vol 42(1), 17; V Ravitsky ,'*Knowing where you come from: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness*', (2010) *Minn J Law Sci Technol*, vol

trace one's genetic origins, while also acknowledging the reasonableness of her arguments. Ravitsky recognizes that some donor-conceived persons who are not able to know their genetic origins may suffer great harm, while others may never suffer any harm. Ravitsky argues, however, that this fact alone does not suffice for denying the need of legal protection for this right, which may (or may not) be realized in reality, depending on the actual circumstances of the donor-conceived person and on what she and her family perceive as best.[50]

Correctly interpreted, Ravitsky argues, the right to know and trace one's genetic origins should not lead to the stigmatization of families whose members are not genetically related. Instead, in its proper interpretation, this right should give appropriate protection to the family members' autonomy in choosing what is in the best interest of their members. For Ravitsky, the right to know and trace one's genetic origins is 'compatible with acknowledging numerous forms of family structures as equally healthy environments for children's development. All it claims is that donor-conceived individuals should be able to choose autonomously what meaning they assign to the component of genetic relatedness in the construction of some of the most fundamental relationships in their lives and in their understanding of kinship'.[51] Ravitsky defends, therefore, the right to know and trace one's genetic origins by arguing that it is required to safeguard and guarantee the right of donor-conceived individuals to autonomously choose whether or not they want to access information about their donors.

Ravitsky's autonomy-based argument is a relevant one. It shows the instrumental value of said right for the realization of the right to autonomously choose what is best for oneself and one's family. Ravitsky's argument, however, does not explain the intrinsic value of the right to know and trace one's genetic origins. To assess whether or not the right to know and trace one's genetic origins has an intrinsic value (on top of this instrumental value that Ravitsky's shows), one needs to assess which distinct moral value this right protects.

11(2), 655.; V Ravitsky, JE Scheib, '*Donor-conceived individuals' right to know*', (2010) Bioethics Forum, http://www.thehastingscenter.org/donor-conceived-individuals-right-to-know/ [Accessed 17 June 2017].

[50] As Ravitsky puts it: 'For some, being donor-conceived may be an important element in the formation of their identities, narratives, and relationships. Others may find it irrelevant or insignificant. But *all* are treated wrongly when they are deprived of the ability to access information about their genetic origins'. (p. 36).

See also: **E** Blyth, '*Donor assisted conception and donor offspring rights to genetic origins information*', (1998) International Journal of Children's Rights vol 6(3), 237-253; E Blyth, (2012) '*Access to genetic and birth origins information for people conceived following third party assisted conception in the United Kingdom*', (2012) International Journal of Children's Rights vol 20(2), 308-318; E Blyth, L Frith, C Jones, and J Speirs, *'The role of birth certificates in relation to access to biographical and genetic history in donor conception*', (2009) International Journal of Children's Rights vol 17(2), 207-233.

[51] V Ravitsky, '*Autonomous Choice and the Right to Know One's Genetic Origins', (2014)* Hastings Cent Rep, vol 44(2), 36.

The purpose of the right to know and trace one's genetic origins is to protect the distinct moral value of biological/genetic relatedness -- without downgrading the importance of the other non-biological components of family tie and personal identity. In other words, the biological/genetic relatedness and the other non-biological components of family tie and personal identity are on a moral par: they are compatible, uniquely invaluable, and incommensurable. Each has its distinct intrinsic moral value, and one is not in competition with the other. There is nothing in affirming the distinct moral value of the biological/genetic relatedness that entails the relegation of the distinct moral value of other non-biological components of family tie and personal identity. In this respect, there is something distinct about the biological/genetic components of family tie and personal identity, and there is *also* something distinct about non-biological components of family tie and personal identity.

Regarding, however, specifically the biological/genetic relatedness between genetic parents and offspring, its distinctness lies in the unique form of tie – a biological/genetic tie -- which is permanent and irreplaceable by its very nature, even if circumstances lead to a separation of genetic parents and offspring. Moschella explains the uniqueness (i.e., the distinct moral value) of this tie as follows. The biological/genetic relatedness is first and foremost a bodily relationship: there is a material and formal causal link, established at the moment of conception and in the act of giving birth. This bodily relationship is made explicit by the fact that the genetic material of the offspring comes from his/her genetic parents. As she puts it: 'The [genetic] parents' combined gametes are the material and partial formal cause of their child's existence and identity as a human organism, which in turn is the basis of that child's overall continuity of personal identity over time'.[52] Unless truncated, this bodily relationship then naturally unfolds, Moschella argues, into a psychological, an intellectual, and a volitional relationship between genetic parents and their offspring.

For Moschella, the biological/genetic relatedness is, in a nutshell, a deeply personal relationship, because genetic parents and offspring share some unique characteristics (at first at the material level, and then subsequently at the psychological, intellectual, and volitional levels). It is in this sense that she argues that the biological/genetic relatedness is irreplaceable and permanent. The irreplaceability and permanence of such tie, she contends, is grounded on the idea that 'the child is who he is because of who his parents are; to be begotten by other parents is, simply, to be someone else'.[53] And she concludes that 'biological (i.e., genetic) parents are, and always will be, unique and irreplaceable to their children even if they have no further interactions with those children beyond

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[52] M Moschella, '*Natural Law, Parental Rights and Education Policy*', (2014) The American Journal of Jurisprudence, vol 59 (2), 197, 205.

[53] Moschella, (n 66).

conception'.[54] In brief, for Moschella, biological/genetic parents contribute something unique (i.e., their genetic material, at the very least) to that child, and such contribution is permanent and irreplaceable, even if this initial bodily relationship is then truncated and even if it eventually loses significance (to the point of becoming unimportant for some) in comparison to the non-biological components of family tie and personal identity.

Moschella's argument is key in clarifying what the distinct moral value of the biological/genetic relatedness is, and why therefore the conceived child's right to know and trace one's biological is morally significant. But opponents of the right to know and trace one's biological origins might still insist that this line of reasoning is discriminatory against non-biological family ties. It is undoubtedly true that parenthood does not solely depend on or derive from the biological/genetic tie that is formed at the moment of conception and in the act of giving birth. In fact, parenthood does not depend on or derive from the biological/genetic tie at all in the case of adoption. The example of adoption gives an indication, first, that an excessive preoccupation with and sole focus on the biological/genetic aspects of parenthood are misplaced. Second, it also indicates that a parent-child relationship is predicated first and foremost on the volitional (i.e., intentional) dimension of the relationship, rather than on the biological dimension.[55] Will and commitment to form, raise, and love the child are, really, the defining elements of parenthood. Yet again, this needs not to negate the distinct moral value of the biological/genetic relatedness, and therefore it needs not to conflict with the conceived child's right to know and trace one's biological origins.

As mentioned above the right to know and trace one's biological origins derives from the very nature of the genetic parent-child relationship, which is a unique, permanent and irreplaceable relationship. It is in this sense that the right to know and trace one's biological origins is a natural and basic human right. First, it is a natural right because, in being predicated on the genetic/biological relationship that exists between genetic parents and offspring, this right does not derive from the state's authority, and does not depend on its political institutions to exist or be conferred existence. In other words, the right to know and trace one's genetic origins is a natural, pre-political, and pre-state right: this right exists even if the state and its political institutions do not recognize it; also, the state cannot usurp such right from any human being. Second, in having intrinsic value, the right to know and trace one's genetic origins has a distinct moral relevance that is basic (i.e., fundamental, primordial) for the exercise of other subsequent rights (e.g., the right to autonomously choose what meaning to

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[54] Moschella, (n 66).

[55] See T Callus, '*A New Parenthood Paradigm',* (2012) Legal Studies*,* vol *32,* 347.

assign to the genetic component of one's identity).[56] And third, the right to know and trace one's genetic origins is a human right because it is predicated on one's humanity and dignity, applying universally to every human being without discrimination, just by virtue of his/her being a member of the human family.

2. The Regulations vs. The Right to Know and Trace One's Genetic Origins

If the right to know and trace one's genetic origins is a natural and basic human right that applies to all human beings without discrimination, then it needs to apply to all human beings, irrespective of their mode of conception. This means that the right applies to both naturally and donor-conceived children – which include all donor-conceived children, regardless of the particular technique of conception. Differences in the mode of conception seem not to be morally relevant reasons to negate the right to know and trace one's genetic origins to a particular group of children, simply because they are donor-conceived in a particular way. Children born as a result of mitochondrial donation and replacement procedure should, therefore, have the same rights as other children, born naturally or as a result of other ARTs and IVF techniques. In short, the right to know and trace one's genetic origins should *prima facie* apply to donor-conceived children born as a result of the mitochondrial donation and replacement procedure as well.

If the right to know and trace one's genetic origins is a natural, pre-political, and pre-state right, then this basic human right exists even if the state and its political institutions do not recognize it as a legal right. More importantly, the state cannot usurp such natural right from any human being. However, by negating the legal right of the conceived children to know and trace their genetic origins, the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 are not only discriminating against children born as a result of the mitochondrial donation but also usurping (i.e., violating) their natural and basic human right.

By restricting the rights of the children born as a result of the mitochondrial donation, and allowing them to access only 'limited'[57] and 'non-identifying'[58] information about their donors, the Regulations

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[56] V Ravitsky, '*Autonomous Choice and the Right to Know One's Genetic Origins', (2014)* Hastings Cent Rep, vol 44(2), 36, 37.

[57] Sarah Barber, Peter Border, '*Mitochondrial Donation*', (29 January 2015), 23 <researchbriefings.files.parliament.uk/documents/SN06833/SN06833.pdf> [Accessed 5 July 2017].

[57] Barber, Border (n 71).

[58] 'Informing mitochondrial donors about information available to children born from the treatment

33.28 - The centre should inform mitochondrial donors that anyone born as a result of their mitochondrial donation will have access to the following non-identifying information provided by them, from the age of 16: a) the screening tests are marred by an ethical as well as a legal problem. The ethical problem pertains the aforementioned unjust discrimination against children born as a result of the mitochondrial donation, and the usurpation of their natural and basic human right to know and trace their genetic origins. The legal problem relates specifically to the fact that the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 contradict both the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004/1511 and the 1990 Human Fertilisation and Embryology Act (as amended), which had permitted that details about egg, sperm, or embryo donors, registered after 1 April 2005, be passed on to the offspring.[59] As discussed above, this 2004 amendment to the 1990 Act gave donor-conceived children the right to know and trace the name and last address of their sperm, egg, or embryo donors, giving thus full access the identity of their donor upon reaching the age of 18.[60] But the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 now restricts the rights of the children born as a result of mitochondrial donation and replacement procedure.

The ethical and the legal problems of the Regulations are intertwined thus: by contradicting previous legislations and unjustly restricting the human rights of the children born as a result of mitochondrial donation and replacement procedure, the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 not only create an unjust discriminating against these children but also usurp one of donor-conceived children natural and basic human rights.

An amendment of the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 would, therefore, be justified on the basis that children born as a result of mitochondrial donation and replacement procedure should not have fewer rights than other children conceived with donor eggs or sperm. In other words, if children born as a result of mitochondrial donation should not be deprived of the right to access the same kinds of information to which other children also conceived with donor eggs or sperm have access,[61] and if the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 deny them access to the identity of their donors,[62]

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carried out on the mitochondrial donor and information on that donor's personal and family medical history b) matters contained in any description of the mitochondrial donor as a person which that donor has provided, and c) any additional matter which the mitochondrial donor has provided with the intention that it be made available to a person born from their donation'. < http://www.hfea.gov.uk/9931.html#guidanceSection10051 > [Accessed 5 July 2017].

[61] The Anscombe Centre, '*HFEA consultation on Mitochondrial Replacement*', (2013). <http://www.bioethics.org.uk/images/user/HFEAmitochondrialsubmission.pdf> [Accessed 5 July 2017].

[62] 'Regulations 11 to 15 modify the information provisions in the 1990 Act to enable children born following mitochondrial donation to access limited, non- identifying, information about their mitochondrial donor. Provision is also made for a mitochondrial donor to access limited, non-identifying, information about children born from their donation, although they will not be notified about requests for information'. The Human Fertilisation and Embryology (Mitochondrial Donation)

then the UK Government should now revisit their original decision and amend the Regulations so to redress such discrimination.

The UK Government based its original decision of denying identifying information to children born as a result of mitochondrial donation on the opinion of the majority of IVF and mitochondrial donation experts. Both the Nuffield Council on Bioethics and the Human Fertilisation Embryology Authority recommended that the right to know and trace one's genetic origins should not be recognized in the case of mitochondrial donation and replacement procedure.[63] The majority believed that mitochondrial donors should be treated more as tissue donors than gamete donors.[64] This is because, in their opinion, 'the tiny amount of mtDNA [donated mitochondrial DNA] contributes little or nothing to [the] personal characteristics'[65] of the children born as a result of the mitochondrial donation. As mentioned above, the scientific community is divided on this topic. Those who disagree that mitochondrial donors could be equated to mere tissue donors emphasize that donor-conceived embryos have three parents and that they are the result of the father's sperm, the mother's egg, and the donor's egg.[66] As Reuven Brandt puts it: 'mitochondrial donation results in a child who inherits genetic material from three different individuals.'[67]. In their view, the third individual (or parent) donated not merely her tissues, but her egg (containing her healthy mitochondria). Were mitochondrial donation a mere tissue donation, they contend, it would not be incorporated into each and every cell of the body of the conceived child; neither would it be transmitted down the germline.[68]

Regulations 2015. Explanatory note. <http://www.legislation.gov.uk/ukdsi/2015/9780111125816/note>. [Accessed 5 July 2017].

[63] Reuven Brandt, '*Mitochondrial donation and "the right to know"*', (2016) Journal of Medical Ethics, vol 42, 678.

[64] Sarah Barber, Peter Border, '*Mitochondrial Donation*', (29 January 2015), 22 <researchbriefings.files.parliament.uk/documents/SN06833/SN06833.pdf> [Accessed 5 July 2017]

HFEA, '*Mitochondria replacement consultation: advice to Government*', (March 2013), 24. < http://www.hfea.gov.uk/docs/Mitochondria_replacement_consultation_-_advice_for_Government.pdf> [Accessed 5 July 2017].

[65] Barber, Border, (n 78);

HFEA, '*Mitochondria replacement consultation: advice to Government*', (March 2013), 21. <http://www.hfea.gov.uk/docs/Mitochondria_replacement_consultation_-_advice_for_Government.pdf> [Accessed 5 July 2017].

[66] Reuven Brandt, '*Mitochondrial donation and "the right to know"*', (2016) Journal of Medical Ethics, vol 42, 678.

D A Jones, '*The other woman: evaluating the language of 'three-parent' embryos*', (2015) Clinical Ethics, vol 10(4), 97, 101.

[67] Reuven Brandt, '*Mitochondrial donation and "the right to know"*', (2016) Journal of Medical Ethics, vol 42, 678.

[68] The authors are grateful for Trevor Stammers for clarifying this point.

This is a protracted scientific debate that will not be quickly resolved. However, finding common ground between the two opposing positions in this discussion is a pivotal approach if one wants to shed light on the disagreements with the aim of moving towards future convergence. Although the scientific community is divided, the opposing sides of the debate can at least agree that each of these three individuals (i.e., the father, the mother, and the donor) contributed something unique -- even if 'minimal' or 'no detectable'[69] -- to the conceived child. Certainly, the opposing parties in the debate would disagree on the relevance and degree of such contributions. One side would argue it is negligible, the other would contend it is substantial; and possibly there would be middle-ground positions, too. However, they could all at least agree with the fact that each of these three individuals (i.e., the father, the mother, and the donor) contributed something unique to the conceived child, regardless of the relevance and the degree of said contribution.

Now, if this is the common ground (i.e., the fact that these three individuals contributed something unique to the conceived child), one could stretch it a bit further to argue that the donor's egg and her healthy mitochondria are a contribution that cannot be so easily dismissed. Even if her (i.e., the donor's) mtDNA is 'minimal' or 'no detectable'[70] in the genetic make-up of the donor-conceived embryo, her egg and healthy mitochondria are a contribution – and a vital one – nevertheless: were it not for the donor's egg and her healthy mitochondria the conceived child (free from mitochondria diseases) would not have existed.

Now, if (i) based on the common ground, people can agree that in the mitochondrial donation and replacement procedure three people contribute something unique to that conceived child.[71] And if, as argued above, (ii) people could also agree that biological/genetic parents contribute something unique (i.e., their genetic material, at the very least) to the child, and such contribution is permanent, irreplaceable, and morally distinct. Then, the logical conclusion that should be agreeable is that all the three individuals (i.e., the father, the mother, and the donor) should be considered the

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[69] Sarah Barber, Peter Border, '*Mitochondrial Donation*', (29 January 2015), 22 <researchbriefings.files.parliament.uk/documents/SN06833/SN06833.pdf> [Accessed 5 July 2017]

L Craven, H A Tuppen, G D Greggains, et al., '*Pronuclear transfer in human embryos to prevent transmission of mitochondrial DNA disease',* (2010) Nature, vol 465, 82.

[70] Sarah Barber, Peter Border, '*Mitochondrial Donation*', (29 January 2015), 22 <researchbriefings.files.parliament.uk/documents/SN06833/SN06833.pdf> [Accessed 5 July 2017]

L Craven, H A Tuppen, G D Greggains, et al., '*Pronuclear transfer in human embryos to prevent transmission of mitochondrial DNA disease',* (2010) Nature, vol 465, 82.

[71] Reuven Brandt, '*Mitochondrial donation and "the right to know"*', (2016) Journal of Medical Ethics, vol 42, 678.

D A Jones, '*The other woman: evaluating the language of 'three-parent' embryos*', (2015) Clinical Ethics, 10 (4).97, 101.

genetic/biological parents of the conceived child, the conceived child should have the right to know and trace her three different genetic/biological origins. Such is her natural and basic human right, and it cannot be so quickly usurped by the government only because the government is of the opinion that the egg donor's contribution is negligible.

Conclusion

This paper discussed the purpose of Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572, as well as one fundamental ethical and legal challenge that this legislation overlooks: the right of the conceived children to know and trace their genetic origins.

The paper argued that this is a natural and basic human right, guaranteed by legal documents in the UK and internationally, and also morally justified. By negating the conceived children's right to access her egg and mitochondrial donor's information, the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572 negates the right of the conceived children to know and trace their genetic origins. In doing so, the Regulations not only violate a natural and basic human right but also creates a discrimination against three-parent children, given that all other IVF donor-conceived children have the right to know and trace their biological origins. For this reason, the Regulations should be amended to specificity remedy said discrimination.