



AUSTRALIAN CATHOLIC BISHOPS CONFERENCE

Bishops Commission for Family, Youth and Life

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11 May 2018

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Dear Sir/Madam

Science of mitochondrial donation and related matters

This submission is from the Australian Catholic Bishops Conference (ACBC) as prepared by the Bishops Commission for Family, Youth and Life (BCFYL).

The ACBC is the assembly of Catholic Bishops of this country and the means by which the Bishops act nationally and address issues of national significance.

The BCFYL is one of the commissions established by the ACBC to address important issues both within the Church and the Australian community. The BCFYL has responsibility for bioethical issues.

The Catholic community is the largest religious group in Australia with more than one in five Australians identifying as Catholic. The Church provides Australia's largest non-government grouping of hospitals, aged and community care services, providing approximately 10 per cent of healthcare services in Australia. It provides social services and support to more than 450,000 people across Australia each year. It has over 1730 schools enrolling more than 760,000 Australian students.

The ACBC seeks to participate in public debate by making reasoned arguments that can be considered by all people of goodwill.

The ACBC appreciates the opportunity to make a submission to the Committee's inquiry into the *Science of mitochondrial donation and related matters*.

Summary

The ACBC has grave concerns about the techniques described as mitochondrial donation because:

- The methods used to create and discard new human life do not respect the right to life and the human dignity of the individuals concerned;
- The methods would confuse the parentage of any children born, risking their right to know and be raised by their natural parents;
- One of the techniques - pronuclear transfer – is a form of human reproductive cloning, which is unethical;
- These techniques will not provide cures for disease, but instead ensure that someone is not born with abnormal mitochondria and the potential for a mitochondrial disease to develop
- There are significant risks and inconvenience to the women who will be asked to provide eggs to enable these procedures
- There are significant risks to the community because these techniques can change the human germline
- There are alternative ways of forming a family while avoiding transmitting mitochondrial disease, including adoption, and
- Australia has limited resources available for research and healthcare. Given the manifest risks and ethical problems raised by mitochondrial donation, these techniques should be rejected.

Introduction

Mitochondrial donation encompasses a number of techniques designed to ensure that children whose mothers have abnormal mitochondria can be born free of that condition. Mitochondrial abnormalities can lead to a wide range of medical conditions of varying severity including Leigh syndrome, diabetes, deafness and epilepsy.¹ Our hearts go out to families dealing with these diseases and who have the understandable desire that their children should not also be born with these burdens. It is a natural human longing to spare children of illness and suffering. The hope offered by mitochondrial donation however comes with its own dangers to the human germline, to the natural family by creating three parent human embryos and to human dignity. Adoption or fostering would offer a simpler path. Mitochondrial donation is not in the best interests of parents and children, let alone the broader community.

This submission primarily addresses point (b) of the Committee's terms of reference, which is "the safety and efficacy of these techniques, as well as ethical considerations."

¹ Dimond, R, Social and ethical issues in mitochondrial donation. *British Medical Bulletin*, Volume 115(1), 1 September 2015, Pages 173–182.

Assisted Reproductive Technology

Mitochondrial donation forms part of the broad spectrum of Assisted Reproductive Technology (ART). The ACBC does not believe that ART is in the best interests of prospective parents, nor their hoped for children, because it raises issues affecting the dignity of each of the participants.²

Human beings have inherent dignity and their rights as people must be respected including their right to life from the moment that the first cell of the human zygote is formed by whatever means it comes to be.³

A logical ethical sequence of this dignity is that the life of each human embryo is to be considered inviolable. ART may involve the discarding of human embryos and may involve the formation of an embryo by a laboratory procedure replacing the personal, life giving nature of the intimate expression of love through marital intercourse between husband and wife with a technical procedure.⁴ Children should be welcomed with unconditional love.⁵

The interests of children are paramount and this is a principle upheld in international law to which Australia is a signatory⁶. Children have a right to an identity and family relations⁷, and as far as possible, the right to know and be cared for by⁸, and maintain personal relations and direct contact with, both natural parents.⁹

Further, the use of donor gametes including gametes from more than two parents threatens the above rights of the child to inherit his or her relationship to natural parents.

On the same basis, the relationship between a parent and a child requires an awareness that it has a life-long character, and that each parent – just like the child – has a right and responsibility to know, in as far as is possible, their child or children, and that such a right cannot be discretely put aside with the promise of anonymity or for the purposes of economic or social expediency.

² Congregation for the Doctrine of the Faith, *Donum Vitae: Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day*. 22 February 1987, #5; Instruction Dignitas Personae on Certain Bioethical Questions, 20 June 2008, #16.

³ Instruction Dignitas Personae on Certain Bioethical Questions, 20 June 2008, #4, 6.

⁴ Instruction Dignitas Personae on Certain Bioethical Questions, 20 June 2008, #16; Catholic Health Australia, *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*. Catholic Health Australia, 2001. #2.1.

⁵ Anscombe Bioethics Centre, Response to the Nuffield Council Report on Mitochondrial Donation, 24 February 2012.

⁶ UN *Convention on the Rights of the Child* Art. 21
<http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

⁷ Ibid. Art. 8

⁸ Ibid. Art. 7

⁹ Ibid. Art. 9

The ACBC, therefore, is critical of the provision of ART services because of these significant ethical concerns and the violation of the human dignity and rights of the child as an embryo and as a child born or to be born.

Human dignity

Human dignity is the dignity unique to human beings and the basis of all human rights. This human dignity is possessed by each and every human being, irrespective of their age, sex, race, abilities, or any other quality. Since human life is continuous from conception to natural death, the inherent dignity and right to life of every person must be respected from the moment that the first cell of the human zygote is formed by whatever means it comes to be.¹⁰ The practice of ART clearly compromises the human dignity of people in the earliest stage of their development.

The nature of ART is that it tips the balance of respect away from people born as a result of ART to the intending parents.

ART presumes that 'respect' is owed to the human person born as a result of ART regardless of the procedure by which that person was conceived. We share the commitment to respect for each individual human person, from conception until natural death, yet urge that this respect for the persons conceived must also be manifest in the manner by which they are conceived (i.e. by the process of conception itself). If respect is not inherent in the manner by which a person is conceived and if conception is treated merely as a mechanical means of production, then respect is denied to the child conceived at the very origin of their life.

What is mitochondrial donation?

Mitochondrial donation is a method to ensure that mothers who have abnormal mitochondria can give birth to a child who does not have abnormal mitochondria. Mitochondrial DNA (mtDNA) is inherited from the maternal line as it originates from ova.¹¹ mtDNA is an important influence on characteristics such as ageing, memory and combatting disease.¹²

The methods for mitochondrial donation include pronuclear transfer and maternal spindle transfer.

Pronuclear transfer (PNT) is where two human embryos are created, one with abnormal mitochondria and the other human embryo created with a donor ovum. Each embryo is enucleated, meaning the nuclear DNA (nDNA) is removed. The nDNA is

¹⁰ Instruction Dignitas Personae on Certain Bioethical Questions, 20 June 2008, #4, 6.

¹¹ Haimes, E and Taylor, K, Sharpening the cutting edge: additional considerations for the UK debates on embryonic interventions for mitochondrial diseases. *Life Sciences, Society and Policy* (2017), 13: 1, page 3.

¹² Cussins, J and Lowthorp, L, Germline modification and policymaking: the relationship between mitochondrial replacement and gene editing. *The New Bioethics*, Vol 24(1), 2018, page 82.

moved from the embryo with abnormal mitochondria and transferred to the healthy embryo.¹³ Two human embryos are destroyed in this process to create a third.¹⁴

The new human embryo would have three genetic parents, nDNA from the father, nDNA from the intending mother with abnormal mitochondria and mtDNA from the egg donor mother who provides the egg.¹⁵ In the case of a second sperm donor father, the child could have four parents.¹⁶

The ACBC objects to the disposing of any human embryos because such actions would instrumentalise human embryos, treating them as part of a production process where they can be kept or disposed of subject to arbitrary judgements.¹⁷ This of course does not show respect for the embryos' inherent human dignity.

Maternal spindle transfer (MST) is another technique for ensuring that damaged mtDNA is not passed on to children. In this case, nDNA is moved from the intending mother's unfertilised egg to the egg donor mother's egg which has had nDNA removed. The reconstructed egg is then fertilised to create a human embryo.¹⁸ MST also involves three genetic parents and the difficulties that come from that confused parentage for the child.¹⁹

It is sometimes argued that the mtDNA provided by the woman who provided the donor egg is so small as to be ethically unimportant, but of course without a small amount of genetic material in the form of mtDNA the whole technique would not work.²⁰

Haimes and Taylor point out that "the term 'mitochondrial donation' implies that the egg provider contributes only mitochondria; however, her 'host' egg contains not only mitochondria but also all the other cellular structures and chemicals required by the intending parents' nuclear DNA to direct the egg to develop into an embryo."²¹

¹³ Amato, P et al, Three-Parent IVF: Gene Replacement for the Prevention of Inherited Mitochondrial Diseases. *Fertil Steril*, 2014 January; 101(1) page 31-35; Blesa, JR et al, Ethical aspects of nuclear and mitochondrial DNA transfer. *The Linacre Quarterly*, 83(2) 2016, page 183.

¹⁴ Anscombe Bioethics Centre for Healthcare Ethics, submission to the Human Fertilisation and Embryology Authority's consultation on mitochondrial replacement, 2013.

¹⁵ Haimes, E and Taylor, K, 2017, page 2; Anscombe Bioethics Centre for Healthcare Ethics, submission to the Human Fertilisation and Embryology Authority's consultation on mitochondrial replacement, 2013.

¹⁶ Anscombe Bioethics Centre for Healthcare Ethics, submission to the Human Fertilisation and Embryology Authority's consultation on mitochondrial replacement, 2013.

¹⁷ Velez, J, An Ethical Comparison between In-Vitro Fertilisation and NaProTechnology. *The Linacre Quarterly*, Vol. 79(1), page 61.

¹⁸ Amato, P et al, 2014, page 31-35.

¹⁹ Anscombe Bioethics Centre, Response to the Nuffield Council Report on Mitochondrial Donation, 24 February 2012.

²⁰ Haimes, E and Taylor, K, 2017, page 12.

²¹ Haimes, E and Taylor, K, Rendered invisible? The absent presence of egg providers in the UK debates on the acceptability of research and therapy for mitochondrial disease. *Monash Bioeth Rev* (2015) 33: 365.

These techniques are not cures for disease, but instead ensure that someone is not born with a disease or with the potential for an illness to emerge.²² In two highly publicised cases, Charlie Gard²³ had mitochondrial disease and it was speculated that Alfie Evans might have had a similar condition.²⁴

Putting resources into mitochondrial donation will not help those people who are already born and have a mitochondrial condition, but only ensure some people are not born with mitochondrial disease caused by abnormalities in the mtDNA. Not all forms of mitochondrial disease are caused by abnormalities in the mtDNA.²⁵

Language which masks the same techniques as human cloning

The language used in debate over these techniques is important. Terms like mitochondrial donation, mitochondrial transfer, mitochondrial manipulation and mitochondria replacement therapy are misleading because they don't describe what is happening with PNT or MST. In fact it is the nDNA that is moved, not the mtDNA.²⁶

Baylis emphasises "this shift in language is 'scientifically inaccurate and ethically misleading' – it masks the fact that the micromanipulation techniques involved are the same techniques used for nDNA germline modification and human somatic cell nuclear transfer (i.e. cloning)."²⁷ This reference to human reproductive cloning is a reference to PNT.²⁸

Lane et al state that "MRT [mitochondrial replacement techniques] is thus a misnomer for nuclear transfer [human cloning], which is prohibited by criminal sanctions under sections on reproductive cloning in ... Australia ...".²⁹

The risks of mitochondrial donation

There are important safety issues to be considered with Haimes and Taylor pointing out that "medicines or medical devices that do not behave as safely as expected might well affect the first individuals to receive them, but PNT/MST are interventions of a

²² Blesa, JR et al, 2016, page 187

²³ Charlie Gard: 'Beautiful little boy' at heart of UK legal dispute dies. *ABC News*, 29 July 2017, see: <http://www.abc.net.au/news/2017-07-29/charlie-gard-beautiful-little-boy-at-heart-of-dispute-dies/8755714>

²⁴ What is mitochondrial DNA depletion syndrome and does Alfie Evans have it? *Newsweek*, 26 April 2018. See: <http://www.newsweek.com/what-mitochondrial-dna-depletion-syndrome-and-does-alfie-evans-have-it-902928>

²⁵ Haimes, E and Taylor, K, 2017 page 10-11.

²⁶ Baylis, F (2017) Human nuclear genome transfer (so-called mitochondrial replacement): clearing the underbrush. *Bioethics*, Vol 31(1), page 11; Haimes, E and Taylor, K, 2015, page 364; Cussins, J and Lowthorp, L, 2018, page 77.

²⁷ Baylis, F, 2017, page 11.

²⁸ Anscombe Bioethics Centre for Healthcare Ethics, submission to the Human Fertilisation and Embryology Authority's consultation on mitochondrial replacement, 2013.

²⁹ Lane, A et al, 2016, page 731.

different order, with the potential to affect the whole human species, rather than a series of individuals, because they change the germline.”³⁰

Changing the human germline means a person’s changed genome is heritable by their children. In the case of mtDNA, the changes are heritable from mother to daughter. This presents unknown risks to future generations.

Lane et al note that “research regarding the long-term safety and efficacy of MRT [mitochondrial replacement techniques] and the certainty that MRT will result in the birth of a child without a mitochondrial disease has not yet been undertaken.”³¹

Without proof of the safety of these techniques, the potential benefits to a number of families would come with a risk to the common good.³²

The source of human eggs for mitochondrial donation

There are also risks associated with the provision of human eggs.

Both MST and PNT require significant supplies of human eggs, both for research and for the techniques if they are permitted. Eggs can only be found by seeking out willing adult women to provide their ova. Neither PNT nor MST have high success rates, so would need more eggs than for IVF.³³

The imposition on those women who decide to provide their eggs cannot be overestimated. An account of the experience of women living in England gives some insight of what might be the experience of Australian women donating their eggs:

- A woman hears or reads about a request for eggs for research
- After some reflection, she completes an online form to express her interest
- “If the young woman fits the initial filtering criteria for egg provision ... the clinic invites her to attend a meeting ...”
- “If she decides to go ahead she is asked to sign a consent form ...”
- “She then undergoes medical screening, including a trans-vaginal ultrasound scan, being weighed and various blood tests to measure her ovarian reserve ...”
- “She travels back to the clinic a couple of weeks later and is instructed on how to give herself injections. Over the next 4 weeks, once a day, she sterilises the tops of medication vials, draws up the dose, swabs a patch of her belly and injects herself.”
- “... she travels to at least two more appointments at the clinic, for scans to ensure she is not hyperstimulating dangerously.”

³⁰ Haimes, E and Taylor, K, 2017 page 7.

³¹ Lane, A et al, 2016, page 732.

³² Haimes, E and Taylor, K, 2017, page 16.

³³ Lane, A et al, 2016, page 733.

- “... she is then taught how to dissolve and dilute a powdered hormone to the required dose. For a week she gives herself two injections of this each day and also attends the clinic for another scan.”
- “If the follicles are developing appropriately she is booked in for an egg collection procedure and she is given the final medication to trigger ovulation and told when she must inject that. She is told that she will need someone to accompany her on the egg collection day and to stay with her for 24 h until the effects of the sedative that she will received for the procedure wear off.”
- “On the day of the egg collection, she is taken through to a small operating theatre where she is given the sedative.”
- “After her eggs have been collected she spends a couple of hours in a recovery room, at the end of which a member of clinic staff asks for a signature and gives her a check for 500 pounds. She can leave.”
- “After a few days of bad cramps she is back at work ...”.³⁴

The significant imposition on the life of a woman providing ova for research or other purposes indicates how difficult it may be to find ova for PNT or MST. This type of process is not in keeping with the dignity of the women who provide ova.

Similar difficulties would also face the intending mother in providing eggs for these procedures.³⁵

There’s also a serious risk to the health of women providing eggs. Cussins and Lowthorp point out that “egg extraction poses a number of serious risks, including memory loss; depression; joint, muscle, and bone pain; formation of blood clots; seizures; ovarian hyperstimulation syndrome (OHSS); and even death.”³⁶

Payments or inducements for egg donors

The ACBC does not support allowing direct or indirect inducements, such as a monetary payment for human gametes and only supports compensation for donors for documented expenses which are directly relevant to the donation. The standard should be the level of expense documentation required by the Australian Taxation Office in relation to documenting work related expenses. The matter of inducements for participation in research was addressed in detail by the Australian Health Ethics Committee in a document which suggested questions for Human Research Ethics Committees to ask in relation to separating reimbursement from offering a financial incentive or inducement.³⁷

³⁴ Haimes, E and Taylor, K, 2015, 362-3.

³⁵ Baylis, F, 2017, page 16.

³⁶ Cussins, J and Lowthorp, L, 2018, page 82.

³⁷ Using the National Statement 1: Payments to Participants in Research, Particularly Clinical Trials. NHMRC, October 2009.

The issues involved in paying for human eggs are also related to a document the NHMRC produced entitled "The commercialization of human tissue and human tissue products" in 2011. The document referred to several issues including:

- the danger that payments would adversely affect the social capital and community benefit involved in altruistic donation for transplantation to the blood, bone-marrow and eye banks;
- creation of perverse incentives leading to vendors acting in ways in which they would not have acted without the inducement, including, for instance, not providing important information such as information about risk activities for infection, or poor people being exploited;
- the genomic significance of tissue or tissue products being sold which contain genetic information thus affecting not only the donor but also family members, especially if the genomic significance involves a unique value;
- the commodification of the donor's body in parts being bought and sold, which many of those who submitted to that enquiry thought involved a loss of respect for human dignity.³⁸

All of those matters are significant in relation to women being paid for egg donation above the reimbursement of documented expenses incurred in the provision of their eggs.

A crucial ethical issue is the commodification of the bodies of the women involved. As Pope John Paul II expressed it, donating tissue is not just a matter of giving away something that belongs to us but of giving something of ourselves, for "by virtue of its substantial union with a spiritual soul, the human body cannot be considered as a mere complex of tissues, organs and functions . . . rather it is a constitutive part of the person who manifests and expresses himself through it".³⁹ He went on to say, "any procedure which tends to commercialise human organs or to consider them as items of exchange or trade must be considered morally unacceptable because to use the body as an "object" is to violate the dignity of the human person."⁴⁰

Allowing inducements would mean treating the human body and hence the person as a mere commodity, undermining the existing social capital in existing systems of donation that depend on altruism and a commitment to the common good, and exploiting the poor who lack alternative ways of earning an income. Individuals and the common good are best protected by maintaining the existing prohibitions on trading in human eggs.

The medical team involved in living organ donation have a special responsibility to ensure the safety of the donor and in general that has proved to be the case. The

³⁸ NHMRC Ethics and the exchange and commercialisation of products derived from human tissue - background and issues 2011 pp 27ff

³⁹ Pope John Paul II [address](#) to the 18th International Congress of the Transplantation Society 2000

⁴⁰ Ibid.

opposite, however, has proven to be true when organs are traded rather than given altruistically and this is a strong reason for opposing trade in human tissue. Further, a key difficulty in allowing the trade in human ova would be it would allow disadvantaged women in need of cash to sell their ova at risk to their own health. Where women are short of money, they are not exercising the choice freely to donate their ova.⁴¹ In fact, to allow women to have true informed consent to donating their ova, inducements must continue to be banned.⁴²

Lane et al emphasise concern with the economic incentives set up by paid egg “donation”, which leads to “... oocytes from socioeconomically deprived women for subfertile couples with more financial resources.”⁴³

There is also the danger of inducements other than money, which are harder to track, such as staff in ART settings offering their ova to please their employer.⁴⁴ Advancing women on waiting lists or giving them a discount rate or not charging for services are all ways which provide an inducement to donate eggs when they might otherwise have been unlikely to do so.

Staff in ART clinics and anyone else in a dependant relationship, such as medical students, should be prohibited from making donations where there is a relationship between the clinic or its staff and the university in which the students are enrolled.

The rights of donor-conceived children

The Committee should also consider the needs of any children conceived by mitochondrial donation. In a sense this is not a new issue at all, with the dangers of such an approach illustrated by the experiences of donor conceived children.

The ACBC submits the biological link between gamete donors and the children who result is of profound significance, which is the reason these links must be recognised and respected.

This includes the right for children to know all their parents. Tobin points out “... the primary point is not the usefulness of this information but access to it being a moral right. That is to say, the idea that one is entitled to know one’s biological parents should be understood primarily as a (moral) right to know the truth about one’s conception as a (or, perhaps, the) fundamental aspect of knowledge of one’s own identity.”⁴⁵

⁴¹ George, K, What about the women? Ethical and policy aspects of egg supply for cloning research. *Reproductive BioMedicine Online*, Vol 15(2), page 132.

⁴² Rao, R, Coercion, Commercialisation, and Commodification: The Ethics of Compensation for Egg Donors in Stem Cell Research. *Berkeley Technology Law Journal*, Vol. 21(3), February 2014. Page 1059.

⁴³ Lane, A et al, 2016, page 733.

⁴⁴ Rao, R, 2014, page 1059.

⁴⁵ Tobin, B, Donor-conceived people: are they entitled to identifying information about their biological parents? *Bioethics Outlook*, 24(1) 2013: 6.

This is about more than ensuring donor-conceived people have access to records and contact details for their biological parents. It is ensuring that the technology is not used so as to prevent a child from knowing the identity of his or her biological parents. Rather it should be a tool for ensuring that the person's right to be identified as the natural child of a biological parent is always respected and that the person's right to have access to his or her biological parents is always respected (even in circumstances in which the law has arranged that he or she cannot make an inheritance claim).

The falsification of a birth certificate so that it does not contain the names of biological parents would be a great wrong to the child. This would create a generation of children dispossessed of their connectedness, personal, biological and cultural to their natural parents and family. It also raises issues about consanguinity; they may unwittingly have children by someone who is in fact a part sibling.

The connections between people and their biological families are so important because:

“... genetic relationship goes to our deepest roots of who we are and to whom we bond. One only has to look at one of the primary uses of the internet – genealogical research – to see how important it is to most of us to know who we come from. And those bonds are not just to parents, but also to brothers and sisters and other genetic relatives. We have ethical obligations to heed these sentiments.”⁴⁶

It should be noted that it is not just a matter of genetics. A child dispossessed of a relationship to a genetic parent, may also be brought up in a totally different culture and feel quite unfamiliar with those who do not share his or her genetic, racial or cultural background. That is not such an issue if the child knows from the outset and is encouraged to form cultural links. However, deception or suppression of information and falsification of records or not keeping accurate records makes it very difficult for the child to later trace his or her family and cultural inheritance.

These genetic relationships are confused by ART as rather than parents being biological, gestational and nurturing, these roles may be split between a number of people:

“Psychologists often refer to the issue of genealogical bewilderment as children, perhaps later in life, seek to discover their origins and to identify their own identity in circumstances in which the genetic parents may be completely unknown to them or become known to them at a later stage. The relationship between a child and his or her parents is complex. So much of our sense of

⁴⁶ Somerville, M, Dispossessed and forgotten: the new class of genetic orphans. *Mercatornet*, 18 September 2007.

identity is based upon that relationship. When it is fragmented, that can be hurtful and confusing.”⁴⁷

In considering the needs of children who will be conceived by ART, “... the principle of ‘anticipated consent’ requires that, when a person seriously affected by a decision cannot give informed consent, we must ask whether we can reasonably anticipate that he or she would consent if able to do so. If not, it is unethical to proceed.”⁴⁸

The frequent frustration that has been expressed by people tracing their natural parents highlights the fact that they would not have consented to decisions being made not in their interests but the interest of their parents and the clinics.

Alternatives to mitochondrial donation

There are a number of alternatives for dealing with mitochondrial disease, which include accepting a child with mitochondrial disease and the supports the community should offer to such families, adoption, fostering and deciding to not have children. None of these options are easy and go against the strong human desire for genetically-related children.⁴⁹ Neither PNT nor MST would be more successful for avoiding mitochondrial disease than the much simpler approach of having an egg donor as part of IVF treatment.⁵⁰

It is also important to remember that mitochondrial diseases have varying levels of seriousness and that “... the women who are the targeted beneficiaries of PNT/MST have mitochondrial disease themselves and yet have a quality of life that has enabled them to get to the point of wanting to start a family.”⁵¹

Weighing the benefits and risks of mitochondrial donation

As hard as these cases might be, is it really wise to be risking changes to the human germline and crossing various ethical boundaries for a handful of cases?⁵²

There is also a danger in preferencing a particular view of the human person that privileges certain conditions or capacities over others. In this case the danger might be implying people with conditions or disabilities caused by a mitochondrial disorder have lives of less worth than others. It might also mean by extension that responsible parents should use this technology to try to ensure their children are not born with a mitochondrial disorder. This view of the human person would be a mistake.

⁴⁷ Associate Professor Nicholas Tonti-Filippini, Submission No.2 to the NSW Parliamentary Inquiry into Inclusion of Donor Details on the Register of Births, 18 November 2011.

⁴⁸ Tobin, B, 2013, page 6.

⁴⁹ Haimes, E and Taylor, K, 2017, page 4-5; Lane, A et al, 2016, page 732.

⁵⁰ Anscombe Bioethics Centre for Healthcare Ethics, submission to the Human Fertilisation and Embryology Authority’s consultation on mitochondrial replacement, 2013.

⁵¹ Haimes, E and Taylor, K, 2017 page 10.

⁵² Lane, A et al, 2016, page 732.

Once the technology is established, what is initially put forward as assistance in exceptional cases would likely become more routine. There are already plans to extend the use of mitochondrial donation to infertility treatment and it seems likely that, if approved, there would be pressure to use it for other forms of genetic modification.⁵³ One United States fertility doctor talking about mitochondrial donation says “Everything we do is a step toward designer babies ... With nuclear transfer and gene editing together, you can really do anything you want.”⁵⁴

Cussins and Lowthorp warn that “opening the door to the modification of nuclear DNA would be hugely consequential, exacerbating global disparities and likely taking structural inequality to a new, molecular level. Germline modification sold as an ‘add-on’ at fertility clinics could all too easily establish a system of consumer-based eugenics.”⁵⁵

We must “... think carefully about the obligation to expend limited human and financial resources to prevent and treat illness in existing persons, to build physically and socially healthy communities, and to eliminate health inequities – thereby privileging shared needs over individual wants.”⁵⁶

Conclusion

New techniques with the promise of preventing serious conditions like mitochondrial disorders are very welcome, but when there is a possibility they might affect the human germline, they need to meet the highest of safety standards. Such treatments must also meet the highest ethical standards. The intention of the techniques, which are to avoid passing on disease, are laudable but the way this is achieved by creating and destroying human embryos is very concerning.⁵⁷ Mitochondrial donation also does not offer greater benefits in preventing the passing on of abnormal mitochondria than adoption or some simpler IVF techniques. Safety, ethical and efficiency concerns mean mitochondrial donation should not have approval to proceed in Australia.

⁵³ Gomez-Tatay, L et al, Mitochondrial modification techniques and ethical issues. *Journal of Clinical Medicine*, 2017, 6, 25; Lane, A et al, 2016, page 733; Cussins, J and Lowthorp, L, 2018, page 79.

⁵⁴ Mullin, E, The Fertility Doctor Trying to Commercialize Three-Parent Babies, *MIT Technology Review*, 13 June 2017. See: <https://www.technologyreview.com/s/608033/the-fertility-doctor-trying-to-commercialize-three-parent-babies/>

⁵⁵ Cussins, J and Lowthorp, L, 2018, page 88.

⁵⁶ Baylis, F, 2017, page 15.

⁵⁷ Blesa, JR et al, 2016, page 186.

I would be happy to answer any questions the Committee may have. I can be contacted via Mr Jeremy Stuparich, Public Policy Director at the ACBC

Yours sincerely in Christ

(Most Rev.) Anthony Fisher OP
Archbishop of Sydney
Chair, Bishops Commission for Family, Youth and Life