15 Morningside Road
Edinburgh EH10 4DP
SCOTLAND, UK
E-mail: Mail@schb.org.uk

Date: 7 December 2012 – Human Fertilisation and Embryology Authority

Consultation: Medical Frontiers – Debating Mitochondrial Replacement

Consultation response on behalf of the Scottish Council on Human Bioethics:

The **Scottish Council on Human Bioethics** (SCHB) is an independent, non-partisan, non-religious registered Scottish charity composed of doctors, lawyers, biomedical scientists, ethicists and other professionals from disciplines associated with medical ethics.
The principles to which the Scottish Council on Human Bioethics subscribe are set out in the ***United Nations Universal Declaration of Human Rights*** which was adopted and proclaimed by the UN General Assembly resolution 217A (III) on the 10th of December 1948.

The SCHB's response can be shared internally with other Human Fertilisation and Embryology Authority policy teams who may be addressing the issues discussed. They may contact the SCHB again in the future and the SCHB gives permission to do so.

The SCHB is very grateful to the Human Fertilisation and Embryology Authority for this opportunity to respond to the consultation on ***Medical Frontiers – Debating Mitochondrial Replacement***. It welcomes the HFEA's intention to promote public consultation, understanding and discussion on this topic.

Scottish Council on Human Bioethics Response

Permissibility of new techniques

Q1: What are your views on offering (one or both of) maternal spindle transfer and pro-nuclear transfer to people at risk of passing on mitochondrial disease to their child? You may wish to address the two techniques separately.
(Maximum 2500 characters)

Scottish Council on Human Bioethics Response

The desire by parents to have children 'of their own', or at least as much as possible 'of their own', is the driving force behind the popularity of fertility clinics throughout the world.

In addressing the issues raised by the regulation of Maternal Spindle and Pronuclear Transfer, it is very important to examine the deep bonds that exist between parents and their offspring. For example, many parents, as the responsible partners in the creation of life, know intuitively that they belong to

the child and that the child, in receiving life, belongs to them, i.e., there exists a sort of mutual belonging.
The deep sense of loss or incompleteness felt by parents who are unable to be directly responsible for the creation of life in their child is one of the underlying reasons that many seek assisted reproduction rather than adoption. In other words, the fact that prospective parents even consider, let alone undergo, expensive procedures for artificial reproduction indicates the importance they attach to the biology of creation. Such parents are aware, even if subconsciously, that the lack of biological connection may prevent them from feeling a sense of belonging with the child or the child with them.

However, it may be the case that parents who use Maternal Spindle and Pronuclear Transfer may be bringing a child into the world for their own sakes without fully considering the wishes of the future child. That is, the child may want to have a relationship with all his or her biological parents. Though the social or chromosomal parents may concede to tell their child the truth when they are older, they would then have to understand that the child may wish to see and know his or her gametal parent(s) (the donor(s) of the eggs or the fertilised eggs) and express a sort of affection which he or she may already experience. The child may also experience difficulties towards his or her chromosomal or gametal parents with the possibility of feeling a sense of rejection.

Therefore, the possibility of promoting chromosomal transplantation in order to address mitochondrial disorders should not be envisaged until the two following questions have been satisfactorily addressed:

- *the wish most couples express for a child of their own, and*
- *the important bonds that exist between the biological parents and the child.*

If it remains unclear why parents want to have a child of their own, then it remains unclear why Maternal Spindle and Pronuclear Transfer should even be contemplated.

Changing the germ line

Mitochondria replacement will prevent the inheritance of mitochondrial disease and will result in donor mitochondria being passed down the maternal line to the next generation, therefore altering the germ line.

Any changes to a person's mitochondria will be passed down the maternal line through the mitochondrial DNA to the next generation, and if the child is a daughter, to the one after that and so on. This is referred to as affecting the female germ line.
Germ line modifications have never been permitted on embryos before and this may raise important social and ethical questions.

Right to decide

It has been said that modifying the germ line would affect the child's right to an open future. This means that a decision is made, on a future child's behalf, which affects the range of life options which are available to him or her. In the case of mitochondrial disease the decision would be to ensure the future child and their future children are free from disease.
Many people think that a life free from disease is a more open one than a life with mitochondrial disease. Yet the decision to perform mitochondria replacement is an irreversible choice not just for the future child, but future generations too.

A step too far?

A concern we heard in the dialogue events was that mitochondria replacement was tampering with nature. Some feel that germ line modification is a step too far into a natural biological process. Others feel that, because we already intervene in other areas of reproduction and medicine, it doesn't make sense to apply this argument to mitochondria replacement.

Q2: Do you think there are social and ethical implications to changing the germ line in the way the techniques do? If so, what are they?
(Maximum 2500 characters)

Scottish Council on Human Bioethics Response

The SCHB notes that the techniques on offer are not about treating people who are ill but about shaping future children and generations. It is also of the opinion that there are serious social and ethical implications to changing the germ line in the way proposed by Maternal Spindle and Pronuclear Transfer.

Because parents would be intervening, with intent, into the genome (i.e. the complete set of genes, including chromosomal and mitochondrial genes) of their children in Maternal Spindle and Pronuclear Transfer the procedures could be considered as germ-line interventions. This means that genetic modifications may be passed on to a child and all subsequent descendants.
It would be the first time such intentional genetic modifications in descendants is considered and would open the door to further genetic alterations of human beings with unforeseeable consequences. Because of this, intentional germ-line interventions are prohibited under international law. Thus, for the UK to go it alone, without consulting its international partners, and allow both these procedures would create a very serious precedent. It would open the door to germline interventions and result in grave risks for the future. This is a risk that was already recognised by the 1984 Warnock report (Section 12.16).

The SCHB notes that any intervention seeking to modify the human genome of a person before he or she is created is contrary to international law, including the two following legal instruments:

(A) The United Nations Education, Scientific and Cultural Organization (UNESCO) - ***Universal Declaration on the Human Genome and Human Rights*** *(Adopted on 11 November 1997) indicates that:*

Article 24: That 'germ-line interventions' could be considered as a practice that would be 'contrary to human dignity'.

(B) Council of Europe (47 Countries) - ***Convention for the Protection of Human Rights and Dignity of the Human Being with Regard To The Application of Biology and Medicine*** *(ETS – No. 164, Entered into force on 1 December 1999) indicates that:*

Article 13 – Interventions on the human genome

An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.

In this regard, the Explanatory Report for Article 13 mentions that:

91. Interventions seeking to introduce any modification in the genome of any descendants are prohibited. Consequently, in particular genetic modifications of spermatozoa or ova for fertilisation are not allowed. Medical research aiming to introduce genetic modifications in spermatozoa or ova which are not for procreation is only permissible if carried out in vitro with the approval of the appropriate ethical or regulatory body.

92. On the other hand the article does not rule out interventions for a somatic purpose which might have unwanted side-effects on the germ cell line. Such may be the case, for example, for certain treatments of cancer by radiotherapy or chemotherapy, which may affect the reproductive system of the person undergoing the treatment.

Bearing in mind the UNESCO and Council of Europe Statements it would also be important to spell out the international implications of the UK unilaterally pursuing germline genetic engineering. For any female offspring conceived using such techniques in the UK, a question arises relating to the limits

that might be necessarily placed on their reproductive freedoms should they choose to eventually live in other countries in order to prevent germline alterations being transmitted beyond national borders.

Implications for identity

A child born following mitochondria replacement will have nuclear DNA from both its parents, as well as mitochondrial DNA from a donor (mitochondrial DNA contains a very small proportion of a person's total DNA).

What makes us Us?

Mitochondrial DNA, which comprises a very small proportion of total DNA, is thought only to play a role in energy production. Genes are long interlinked chains of our nuclear DNA. It is our genes, together with environmental factors, that shape our physical characteristics and are therefore important to identity. Given this, a mitochondria donor might be thought to be similar to a bone marrow or blood donor. Donors could be seen as contributing to the recipient's health and wellbeing while not influencing the recipient's sense of identity.

An alternative view is that although mitochondrial DNA comprises a very small portion of genes, this is still vital to our genetic makeup. After all, mitochondria can have a devastating effect on health if they do not function normally. Also, as mitochondria are passed down through generations they can be used to trace maternal ancestry.

A further view is that a person's sense of identity is affected by the experience of illness as much as by their genes. Therefore, by preventing mitochondrial disease these techniques will affect a child's identity in a positive way.
The questions around the impact of genes on identity, both in terms of genetic makeup and what makes someone who they are, may be a source of confusion for the future child.

Where did I come from?

Debates about identity are long running – is it a person's genetics or their upbringing which determines who they are? Or a mixture of both? Mitochondria are thought only to play a role in energy production and, are not responsible for any personal characteristics or traits. But what affect is mitochondria replacement likely to have on a person's sense of self?

It may be helpful to look at how donor-conceived children (those born as a result of egg or sperm donation) relate to their donor origins. Research suggests that donor conceived children who learn about their origins early in life are at ease with how they were conceived, and donor conception does not negatively affect their sense of identity. However, donor conceived people who discover their background later in life can become very distressed, finding the knowledge confusing to their sense of who they are and how they relate to their parents.

Q3: Considering the possible impact of mitochondria replacement on a person's sense of identity, do you think there are social and ethical implications? If so, what are they? (Maximum 2500 characters)

Scottish Council on Human Bioethics Response

The SCHB is of the opinion that the donation of an unfertilised or fertilised eggs can certainly not be thought similar to a bone marrow or blood donor. Biological elements partaking in the creation of life are completely different to biological elements that are used in the treatment of an already existing life.

It is noteworthy that as soon as persons become aware of their existence and are not affected by any serious mental disorders, they usually ask themselves questions about who they are. Of course, the answer to such a question may continually be changing and the quest for identity may never really reach a final conclusion.

This understanding of identity is also extremely important when people are brought into existence and who will then ask similar questions. In other words, it becomes important for many people to know who caused them to exist in constructing their social and cultural identity. For example, they may want to identify their ancestors as well as their biological and cultural origins in seeking to recognise, understand and make sense of who they really are.

In the context of new reproductive technologies, however, genes may no longer be as important as previously understood. Even if a couple decided to bring into existence a living child who was self-aware and who did not have any genes whatsoever (as a thought experiment), this child would still experience a sense of kinship (being a child) towards those who brought him or her into existence with the corresponding parent-child bonds.

When parents, children or other relatives, who have been separated for some reason, eventually seek to re-connect with each other, their reasons for doing so are often difficult to articulate. They frequently struggle themselves to understand what they are actually looking for though they do recognise that it is something which, to them, is very important. In some cases, of course, they would like to know if they are at risk of having a genetic or other biological disorder but many studies indicate that they are also doing this out of 'curiosity' which may reflect a deeper reason such as a search for identity, to know more about themselves or 'emotional significance'.
It is indeed recognised that people, who do not have any genealogical roots, may often experience a deep sense of genealogical void or bewilderment; of being cut off from the causes and reasons for their existence which helps them build their identity.

As a result, individuals usually regard these ancestors and family relatives as being a single community who are cemented to each other. For example, children realise that their existence originated from the personal existences of their ancestors and that their own existence is inherently tied to these previous existences. Without these parents or ancestors they would not exist. As a result they begin to understand that a long chain of ancestors resulted in their existence. It is as if one large communion between the child and his or her ancestors was present, in a kind of single block, who are all the cause of each other's existences down the ages (the cause may be genetic, gametal such as an enucleated egg or something else). People appreciate that because they actually exist because of all their forefathers they owe it to them in some way. There is a sense of being dependent on, and even belonging to, these earlier existences. That all these past existences are also seen, in some way, as part of the 'whole' existence of the child. The child knows that he or she only exists because of his or her ancestors and the prior continuum of descent.

In some form, all these existences come into a kind of communion in which there are deep relationships of unconditional acceptance but also responsibility. And this communion does not only exist between parents and their child but with grandparents, siblings, cousins and other family members.

The status of the mitochondria donor

If mitochondria replacement techniques become legal, law makers would have to decide how to classify the mitochondria donor. Questions around the status of the donor and what, if any, information (eg, personal, medical or contact details) should be available to the future child are linked to concepts of identity. Your views on how mitochondria contribute to a person's identity, or sense of identity, may affect what you think about the status of the donor.

For MST a donor egg is needed, for PNT a donor embryo. The donor embryo would either be created especially for this purpose, from donor eggs and donor sperm, or could be donated from a couple undergoing IVF. The donors could be known to the intended parents (eg, a relative or friend) or may be anonymous. Egg donation is an invasive procedure and there can be side effects.

Currently, people donate many different types of tissue for medical purposes. Each one of these donation processes has very specific regulations regarding the rights of the donor.

Sperm and egg donation

People who donate their sperm or eggs can only do so if they agree to be identifiable to any future child. A donor conceived child can also get medical and personal information about the donor and is able to contact them once the child reaches the age of 18.
This is based on the idea that donor conceived children have a legitimate interest in the person or people who contributed to their genetic makeup through supplying half of their nuclear DNA. These children are therefore likely to have inherited personal characteristics, traits and possibly diseases from the donor through their nuclear DNA.

Blood and tissue donation

People who wish to donate blood, bone marrow or other tissue do so anonymously. This is partly because donation of non-reproductive tissue is not seen as key to a person's sense of identity – although in bone marrow donation, some donor DNA is also transferred to the recipient.
Although tissue donors are anonymous, recipients can be said to have a legitimate interest in knowing that their donor is free from any transferable diseases, because this would have an effect on their wellbeing. It is recognised that people who receive certain types of organ transplants, in particular face and heart transplants, often have identity issues after the surgery.

Accessing information

Some dialogue participants thought that the child should have the option of accessing as much information as they like about the donors.
Others felt that there was no obligation on the donor to reveal their identity and that forcing donors to do so may put them off donating. Others still argued that the child would have a legitimate interest in knowing how they were conceived, but not the identity of the donor.

Q4 (a) In your view how does the donation of mitochondria compare to existing types of donation? Please specify what you think this means for the status of a mitochondria donor.

Scottish Council on Human Bioethics Response

Framing the question so that a comparison is made to procedures of organ donation is false and misleading. This is because with organ donation a life is already in existence whereas in the case of chromosomal transplantation between unfertilised or fertilised eggs, the creation of life is being considered which is completely different from a philosophical and deontological perspective.

Q4 (b): Thinking about your response to 4 (a), what information about the mitochondria donor do you think a child should have? (Choose one response only)

Scottish Council on Human Bioethics Response

1. The child should get no information

2. The child should be able to get medical and personal information about the mitochondria donor, but never know their identity

3. The child should be able to get medical and personal information about the mitochondria donor and be able to contact them once the child reaches the age of 18

4. Other

X 5. I do not think mitochondria replacement should be permitted in treatment at all

Please explain your choice
(Maximum 2500 characters)

Scottish Council on Human Bioethics Response

Perhaps one of the most fundamental questions which arises from the use of Maternal Spindle and Pronuclear Transfer is the fact that more than two individuals are participating in the creation of human life. From this perspective, and although pronuclear DNA is extremely important in the creation of a being, it is impossible to just reduce the concept of creator parenthood to the persons who contributed to this DNA.
This is because without an enucleated egg or fertilised egg from another couple, no new life would ever have existed. From an ethical perspective, each of the pronuclei by themselves have no real value as such. They only become ethically meaningful if they are transferred into an enucleated fertilised or unfertilised egg and left to develop. In this regard, all those participating in the process of bringing a life into existence may be considered, in some form and to varying degrees, as the 'real' creators of the creature. They may then also experience some or all the corresponding aspects of parenthood bonds and mutual belonging which arise between creators and their creatures.

In the case of Maternal Spindle or Pronuclear Transfer, it is not only what is being used that is important (and whether DNA, cytoplasm or any other material is considered) but the amount of individual participation in the creative process. A participation which could then also give rise to creator-creature (parent-child) bonds.

With natural reproduction, the 'real' creators and the DNA providers are the two same persons. However, with a number of new fertility procedures, such as the one being proposed, the identity of the 'real' creators becomes very complex and may vary quite considerably. Thus, a real risk exists that the future child may be confused as to the manner in which he or she understands who his or her creator parents really are. This may be important for his or her sense of identity.

A broad societal discussion concerning the relationship between being a creator and parenthood while trying to understand these parent-child bonds is, therefore, necessary when the creation of human life by novel means is contemplated. After all, it is because these creator-creature bonds are seen as extremely important by many couples that they are seeking fertility treatment and making sure that they have a child 'of their own'.

Regulation of mitochondria replacement

Although the HFEA would only allow specialist clinics to offer these treatments if they had the relevant expertise and equipment to do so, there are a number of options for how treatment should be offered. If mitochondria replacement techniques are made available in the UK, the HFEA as the regulating body, will need to decide how to monitor and regulate use. We would only allow specialist clinics to offer these treatments if they had the relevant expertise and equipment to do so. We would also need to answer the following questions:

- When and how should patients be able to access mitochondria replacement?
- Who should decide when mitochondria replacement is used?

The choice to use this technique, rather than other alternatives, will be a matter of personal preference, as well as a clinical decision.
Some people at our public dialogue events thought that couples may have an ethical preference for one technique over the other — for example for MST because it does not involve discarding an early embryo. Others felt that more important factors in choosing between the techniques were safety and cost efficiency.

Options for how treatment is offered might include:

- Clinics and their patients could decide when mitochondria replacement is appropriate in individual cases
- The regulator could decide which mitochondrial diseases are serious enough to require mitochondria replacement and, just for these diseases, permit clinics and patients to decide when it is appropriate in individual cases
- The regulator could decide which mitochondrial diseases are serious enough to require mitochondria replacement and also decide, just for these diseases, when it is appropriate in individual cases

Q5: If the law changed to allow mitochondria replacement to take place in a specialist clinic regulated by the HFEA, how should decisions be made on who can access this treatment? (Choose one response only)

Scottish Council on Human Bioethics Response

1. Clinics and their patients should decide when mitochondria replacement is appropriate in individual cases

2. The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and, just for these diseases, permit clinics and patients to decide when it is appropriate in individual cases

3. The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and also decide, just for these diseases, when it is appropriate in individual cases

X 4. I do not think mitochondria replacement should be permitted in treatment at all

Please explain your choice
(Maximum 2500 characters)

Scottish Council on Human Bioethics Response

The SCHB is of the opinion that chromosomal transplantation should not be taking place since it is contrary to international law.

Moreover, it believes that characterising maternal spindle and pronuclear transfer as 'mitochondria replacement', as is done in the HFEA consultation, is deeply misleading and reflects a manipulation and misunderstanding of what is really being suggested.
With both Maternal Spindle and Pronuclear Transfer, a transfer of chromosomes is taking place from an unfertilised or fertilised egg to another unfertilised or fertilised egg respectively. It is, therefore, not so much a process of 'mitochondrial donation' or 'mitochondrial transfer' but of 'chromosomal transplantation'.

Should the law be changed?

What is mitochondrial disease?

For any cell to work properly, the mitochondria need to be healthy. Unhealthy mitochondria, due to one of two problems within a cell, can cause genetic disorders known as mitochondrial disease. Firstly, by faults in the genes within a cell's nucleus (where the vast majority of DNA is located) that

are required for mitochondrial function. This type of mitochondrial disease can be inherited from the father or mother as nuclear DNA is inherited from both parents.

Mitochondrial disease can also be caused by faults within the small amount of DNA that exists within the mitochondria themselves. Mitochondrial DNA is only inherited from the mother and helps produce a cell's energy. It is this form of mitochondrial disease that could be avoided using the new techniques at the centre of this consultation.

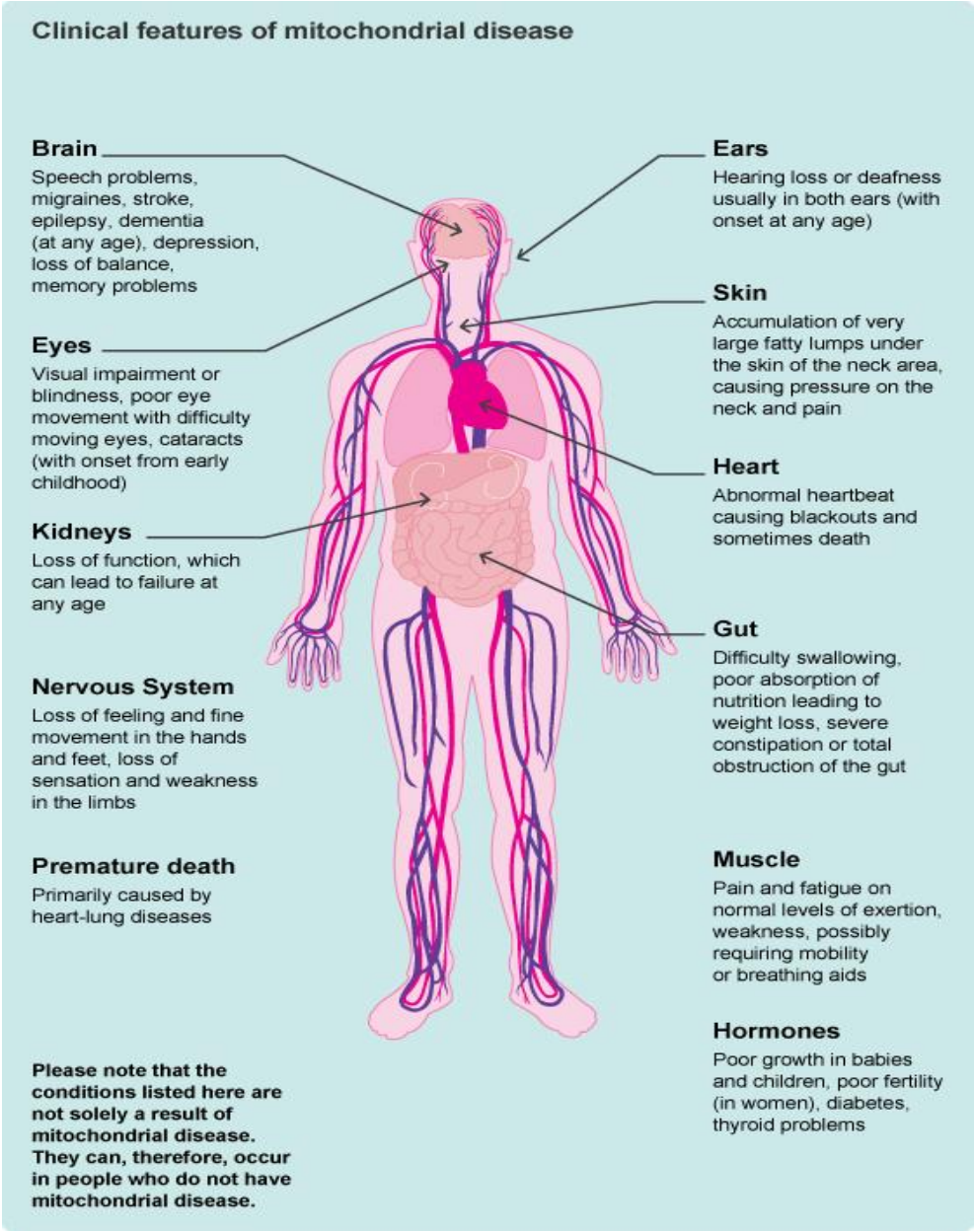
For the purposes of this consultation, all forms of the disease caused by faults in the mitochondrial DNA are grouped together under one title of "mitochondrial disease".
There is a risk that when women with mitochondrial disease conceive naturally, the disease will be passed on to their child. Around one in 200 children are born each year with a form of mitochondrial disease. Some children have mild or no symptoms but others can be severely affected and have a shortened life expectancy.

What effect can mitochondrial disease have?

Mitochondrial diseases vary in terms of severity, depending on the type and extent of DNA defect and the specific gene affected. It also depends on the proportion of healthy versus unhealthy mitochondria within a cell. This is called heteroplasmy. Another important factor is what type of cell is affected. For instance, a faulty brain or a nerve cell will affect someone differently to a person with a damaged muscle cell.

Diseases caused by faults in mitochondria may appear at birth or develop later in life. They are usually degenerative and can affect the functioning of muscles and major organs as well as the nervous system and the cardio-vascular system.
There are many different conditions that are linked to mitochondrial disease. Some are rarer than others, but they include conditions such as Leigh Disease, Barth Syndrome or MERRF syndrome. However, many forms of mitochondrial disease have not been given names as the symptoms are variable from patient to patient so cannot be grouped together as a specific condition.

The diagram below demonstrates some of the problems mitochondrial disease can cause.



Q6: In Question 1, we asked for your views on the mitochondria replacement techniques MST and PNT. Please could you now tell us if you think the law should be changed to allow (one or both of) these techniques to be made available to people who are at risk of passing on mitochondrial disease to their child?
(Maximum 2500 characters)

Scottish Council on Human Bioethics Response

The SCHB is of the opinion that the law should not be changed to allow Maternal Spindle and Pronuclear Transfer to take place.

This is for the reasons already mentioned and because both these procedures could be considered as different forms of eugenic practices since the genome of future children are being intentionally modified through Maternal Spindle and Pronuclear Transfer. These are defined as strategies or decisions aimed at affecting, in a manner which is considered to be positive, the genetic heritage of a

child, a community or humanity in general. As such they would contravene Article 3 of the ***Charter of Fundamental Rights of the European Union*** *(Proclaimed in Nice on 7 December 2000) which indicates that "In the fields of medicine and biology ... the prohibition of eugenic practices, in particular those aiming at the selection of persons" must be respected.*

When a eugenic choice between bringing into existence a disabled or non-disabled person is being considered, it is impossible to separate these persons from their physical characteristics. Any choice in this regard which then becomes public will be seen as very significant by the disabled community since it would suggest that they should not exist. Even once they are born, the very identity of persons and the manner in which they understand themselves as individuals cannot be dissociated from their physical characteristics. In summary, there is a real danger of discrimination to suggest that disabilities, which cannot be separated from persons, should not be brought into existence. This is because the disorder's existence cannot be dissociated from a person's existence. Instead, it is all persons with or without a disability who should be able to be brought into existence without favouritism or bias. In other words, saying that a disorder should not exist, should never mean that a person with such a disorder should not be brought into existence.

The SCHB notes that a significant ethical question would arise if human embryos are destroyed during this procedure.

In this regard, the ***UK Human Fertilisation and Embryology Act 2008*** *defines an embryo in Article 1: (1) (b) as: "an egg that is in the process of fertilisation or is undergoing any other process capable of resulting in an embryo."*

For Maternal Spindle and Pronuclear Transfer to be accepted for clinical use, it is unavoidable that many human embryos will be created solely for research purposes that will, eventually, be destroyed. This creates a serious ethical problem since these human embryos may be considered as having the same moral status (or give the benefit of the doubt) as adult human persons who are then killed for the benefit of others.

Moreover, such a proposal would contravene international law since the ***Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with Regard To The Application of Biology and Medicine*** *(ETS – No. 164, Entered into force on 1 December 1999)*[1] *indicates that:*

Article 18: The creation of human embryos for research purposes is prohibited.

In this regard, the Explanatory Report for Article 18 mentions that:

116. The article does not take a stand on the admissibility of the principle of research on in vitro embryos. However, paragraph 2 of the Article prohibits the creation of human embryos with the aim to carry out research on them.

At present, out of the 47 countries of the Council of Europe only ***two member states*** *(the United Kingdom and Belgium) have publicly indicated that they have no intention, at present, of signing or ratifying this convention. This is because, amongst other things, it would prohibit the creation of human embryos for research through cloning or other procedures (which the UK has already legalised) so that experiments can take place on them for up to 14 days after their creation.*

Furthermore, if Pronuclear Transfer were to be accepted as a form of routine treatment and because UK law defines an embryo as "an egg that is in the process of fertilisation", the procedure would require that at least two embryos are destroyed, each time, to reconstruct a third embryo with new healthy mitochondria. This would be seen as deeply offensive and unacceptable to the millions of people in the UK who believe that personal life begins at the moment of creation of the embryo.

It should also be noted that assisted reproduction is not risk-free for the woman giving the eggs since egg retrieval procedures may risk ovarian hyperstimulation syndrome following aggressive hormonal treatments.

[1] This is a legally binding document when ratified by a country. So far, 29 Member States have ratified this Convention with another 5 signing their intention to ratify. The UK has not signed or ratified this Convention.

Further considerations

Q7: Are there any other considerations you think decision makers should take into account when deciding whether or not to permit mitochondria replacement?
(Maximum 2500 characters)

Scottish Council on Human Bioethics Response

Human procreation does not take place out of thin air. It takes place through the participation of the man and the woman as whole persons. More specifically, this participation takes place through the means of reproductive cells (sperm and egg cells).
In this regard it is important to consider how these reproductive cells can be understood in the context of reproduction.
This is not an easy matter but, generally, each reproductive cell may be considered as a kind of representative of each of the partners in the procreative process. As such, each sperm cell becomes a representative of the whole man and each egg cell becomes a representative of the whole woman.

When parents procreate in a normal way they also give of themselves wholly and unconditionally in the sense that it is not only a portion of the procreating person that takes part in the procreation. It is the whole person that takes part. In other words, when partners participate in the act of procreation they give of themselves to, and accept, the other partner totally, completely and unconditionally in their entire existence. The procreators do not withhold anything from themselves.
This means that when sperm and egg cells participate in the creation of a new person, they express the complete fusion of the whole persons, the parents, from whom they were produced.
When sperm and egg cells participate in the creation of a new being, they can then be considered as 'ambassadors' in the same way as a political ambassador represents, in his or her person, the whole of a country.

Moreover, it should be recognised that the unreserved acceptance between the partners with all their gifts and limitations should also 'expand' onto the child. This means that when partners in a couple accept each other for 'better or for worse' including all their biological disorders, they should unconditionally accept any child resulting from their relationship. This includes all the child's potential disorders, since he or she is brought into existence by the unconditional acceptance of the partners' sperm and egg cells which represent them. The possibility, therefore, of parents selecting or choosing the kind of child they would like to have would mean that they would no longer unconditionally accept each other since they would no longer accept the reproductive cells representing each other's wholeness.

Of course, sperm and egg cells have no moral value of their own but when they come together to form an embryo, their representative wholeness cannot in any way be dismissed as unimportant. On the contrary, it is fundamental since it is the reproductive cells that are the means for procreating another specific 'whole' living child.

This also means that if the sperm and egg cells were significantly modified in a technical manner, such as with Maternal Spindle Transfer, questions can be asked whether they would still represent the wholeness of the partners from whom they originated. Would they not be seen, instead, as being foreign in the same way as if the reproductive cells of a foreign man or woman (i.e. from outside the couple) were used? The procreative process may then be taking place with reproductive cells that no longer represent the partners and could be seen as an intrusion into the exclusive relationship of the couple.

In summary, the proposal to consider Maternal Spindle and Pronuclear Transfer is:

- *too early*
- *contrary to international legal instruments*
- *unclear with respect to consequences*
- *genetic engineering which alters the gene line irrevocably*
- *a precedent that will lead to further engineering and designer babies*

- a suggestion that creates far more problems than it could ever hope to solve, even if the technology does what is says it will do.

Finally, the SCHB notes that new alternatives to both Maternal Spindle and Pronuclear Transfer are already being pursued by scientists in the treatment of mitochondrial disorders which can be considered as far less controversial.[2] These should be examined and developed instead of considering Maternal Spindle and Pronuclear Transfer.

[2] Anonymous, Correcting human mitochondrial mutations, 13 March 2012, e! Science News, http://esciencenews.com/articles/2012/03/13/correcting.human.mitochondrial.mutations, (Accessed on 20 August 2012).