

Published by the Progress Educational Trust

Questions relating to 'mitochondrial replacement'

10 February 2014

By Professor Calum MacKellar

Director of Research, Scottish Council on Human Bioethics

Appeared in BioNews 741

In his response (BioNews 738) to the article 'Should persons affected by mitochondrial disorders not be brought into existence?' (BioNews 736), Professor Sandy Raeburn is right to recognise the suffering experienced by some families affected by genetic disorders including those with disabling mitochondrial conditions. These are individuals and families in which very real suffering and deep distress are present. The compassionate work of Professor Raeburn, and many others like him, who have sought, or are seeking, to alleviate this suffering, through a number of medical treatments, can only be commended.

However, those who are concerned about the possibility of using maternal spindle transfer (MST) and pronuclear transfer (PT) to address mitochondrial disorders do not have any less compassion than those who believe that such procedures should be introduced. It is just that they remain to be convinced that all the biological and/or other risks have been sufficiently addressed.

Professor Raeburn is also right to reference that the advancement of autonomy, the reduction of suffering, and the increase in flourishing of human persons are very important goals in any ethical appraisal. But these aims do not, of course, give any true value or worth to human life. At least not the kind of value and worth that is equal and inalienable to all persons, which is expressed in the concept of inherent dignity by the preamble of the UN Universal Declaration of Human Rights.

Without any doubt, the complex notion of inherent dignity is difficult to define since it cannot just be reduced to scientific or measurable concepts. But this does not make it unimportant since it remains the very basis of civilised society. It is because of inherent human dignity that parliaments, hospitals and suicide prevention programmes exist. It is also because of inherent dignity that persons should actually respect the autonomy of others. Autonomous decisions or even the resolve of a person to live and survive do not give any reasons, in themselves, for others to respect such choices.

If only autonomy or the lack of suffering were the basis of the value and worth of an existing or potential future person, then every human being could be classified as having a different value and worth which would make nonsense of the concept of civilised society.

This is why it is so important to protect the concept of the equal and inviolable inherent dignity of human persons and why it must become central to any ethical discussion relating to actions on human beings no matter how attractive these actions may first appear.

If this concept of equal inherent dignity is gradually undermined by an ever-increasing number of developments working against its very principles, to the extent that it may eventually no longer have any meaning, then the egalitarian basis of societies would be history.

With the complete demise of inherent dignity, there would not even be any reason for the egalitarian aims of the UK's <u>National Health Service</u>.

It is, thus, imperative for a civilised society to always be prepared to equally value, without selection, each and every human individual and to similarly welcome into existence all persons independently of their biological or other characteristics such as their genetic qualities or disorders. This includes persons with or without mitochondrial dysfunctions.

With respect to describing MST and PT as forms of 'mitochondrial replacement' it is difficult not to be confused by such a representation of the procedures.

Certainly the more detailed biological description of both these procedures provided by the <u>Human Fertilisation and Embryology Authority (HFEA)</u> as part of its public consultation made it abundantly clear that it is the chromosomes that are transferred during both procedures, and not the actual mitochondria (1).

Moreover, it should be noted that it is not just new mitochondria that are being used in a defective unfertilised or fertilised egg but a whole new unfertilised or fertilised egg emptied of its maternal spindle or pronuclei, respectively. Mitochondria only form a small part of these new eggs.

The mitochondria are certainly not taken out of one egg and safely transplanted into another egg, from which all or most of the latter's mitochondria have already been removed.

It is, therefore, extremely unfortunate for the HFEA to have used the term 'mitochondria replacement'. Apparently, the aim in using such terminology 'was to enable a lay audience to understand the essential purpose of these techniques' (2). But, in this regard, it is difficult to understand why the HFEA believed that the word 'chromosome' would be far more obscure than 'mitochondria'.

Of course, it is difficult to present new biological procedures to the general public in a simplified manner. But presenting MST and PT as 'mitochondrial replacement' misrepresents reality while making it difficult for the general public to make an informed decision about the procedures and the grave ethical difficulties which they raise for both individuals and the whole of society.

SOURCES & REFERENCES

- 1) New techniques to prevent mitochondrial disease Human Fertilisation and Embryology Authority | 10 February 2014
- 2) Hansard, Columns WA 158-9 House of Lords | *05 December 2012*

RELATED ARTICLES FROM THE BIONEWS ARCHIVE

Response to Professor Calum MacKellar

20 January 2014 - by Professor Sandy Raeburn

Having worked with families affected by genetic disorders for more than 40 years, both in the UK (with its multi-faith society) and in the Sultanate of Oman (where the majority are Muslim but other religions are allowed), I have seen and looked after many people with hereditary illnesses, including those with disabling mitochondrial conditions.... [Read More]

Should persons affected by mitochondrial disorders not be brought into existence?

06 January 2014 - by Professor Calum MacKellar

Mitochondrial replacement techniques are not a form of therapy in which a person is being treated or cured for a disorder, but instead make sure that that certain persons are not brought into existence. This is a crucial difference since it then questions the equality in value and worth of every possible future person... [Read More]

Is mitochondrial replacement therapy eugenic and incompatible with human dignity?

02 December 2013 - by John Appleby, Professor Rosamund Scott and Professor Stephen Wilkinson A group of European parliamentarians from the Council of Europe recently issued a declaration objecting to the HFEA's policy advice on experimental mitochondrial replacement therapy claiming that MRT is eugenic and inconsistent with human dignity. These are substantial moral claims, ones that deserve closer scrutiny, and it is an interesting and important exercise to consider how successful such arguments are... [Read More]