



Open seminar May 17 2013

Mitochondrial replacement for the prevention of mitochondrial DNA disorders - from research to clinical use

Mitochondrial inherited disorders are progressive and may cause very severe disease, suffering and premature death, often affecting babies, children and young people. They are inherited from the mother and can be caused by aberrations in the genes in mitochondrial DNA.

Replacing the mitochondrial DNA by "healthy" mitochondrial DNA from a donated unfertilised or fertilised egg, could help women with a predisposition for mitochondrial diseases to give birth to healthy children. Even future generations will be protected.

Mitochondrial replacement in order to prevent transmission of mitochondrial disorders - raise important ethical questions. On one hand, the technique provides a new opportunity to avoid inherited disorders that can cause severe suffering and premature death. On the other hand, genetic modification of unfertilised or fertilised eggs, has previously been regarded as fundamentally unacceptable and is prohibited in Sweden under the genetic integrity act.

The Swedish National Council on Medical Ethics (Smer) is currently analyzing this issue from an ethical perspective. A report is planned to be published during the autumn 2013. The purpose of this open seminar is to highlight and discuss the ethical issues and questions that the new technology raises.

In the UK, methods for mitochondrial replacement are currently under consideration. Nuffield council published a report on the subject in June 2012. March 20 this year, HFEA published a document concluding a public consultation and advice to the Government regarding the ethics and science of new IVF-based techniques designed to avoid serious mitochondrial diseases. Representatives from the Human Fertilization and Embryology Authority (HFEA) and the Nuffield Council on Bioethics are invited to present the ethical and societal discussion in UK.

Swedish experts are also invited to give presentations about mitochondrial disorders and the scientific and clinical aspects of mitochondria replacement.

Please note that the seminar will be held mainly in English.

Questions to be discussed

- Should it be permitted to use a technique, with the purpose to avoid a serious disease for the future child (and future generations), that will result in a genetic modification that will be inherited? What are the ethical implications? Risks and possibilities?

- Would this be the first step on a slippery slope allowing genetic modification also of nuclear DNA?
- What potential medical and psychological risks are involved for the future child?
- Is there a fundamental need for the technique? Are there alternative treatments to avoid these serious disorders? Would adoption or egg donation be ethically accepted alternatives? PGD or prenatal diagnosis?
- Will the availability of these techniques create pressure to use them? Or is this no different from existing treatments to help couples have healthy children?

Time and place

May 17, 2013, 9.30 – 13.00. Registration and coffee from 9.00, Rosenbad Conference Center. The Government Offices, Drottninggatan 1, Stockholm.

Program

9.30 Opening and welcome *Kjell Asplund*

9.40 Background and patient aspects *Göran Solders, Martin Engvall and Karin Naess*

10.10 Mitochondrial replacement—possibilities and risks *Christoph Freyer and Outi Hovatta*

10.50 Comments *Åsa Nilssonne and Nils-Eric Sahlin*

10.55 Questions and general discussion

11.20 Fruit break

11.40 Nuffield Council on Bioethics report: *Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review* *Hugh Whittall*

12.00 HFEAs recommendations and public consultation *Juliet Tizzard*

12.20 Comments *Elisabeth Rynning, Erik Iwarsson och Göran Hermerén*

12.30 Questions and general discussion

13.00 Closing of the meeting and lunch.

In the program

Kjell Asplund, chair, The Swedish Council on Medical Ethics, Smer

Martin Engvall, MD, PhD, Centre for Inherited Metabolic Diseases, Karolinska University Hospital

Christoph Freyer, MD, PhD, Department of Laboratory Medicine, Karolinska Institute

Göran Hermerén, Professor of Medical Ethics, chair of the Expert Group on Ethics, the Swedish Research Council, expert member Smer

Outi Hovatta, Professor of Obstetrics and Gynaecology, especially Assisted Conception, Department for Clinical Science, Intervention and Technology, Karolinska Institute

Erik Iwarsson, MD, PhD, Consultant Clinical Genetics, Department of Molecular Medicine, Karolinska University Hospital

Karin Naess, MD, PhD, Centre for Inherited Metabolic Diseases, Karolinska University Hospital

Åsa Nilssonne, Professor of Medical Psychology at the Department of Clinical Neuroscience, expert member Smer

Elisabeth Rynning, Justices of the Supreme Administrative Court, former professor in Medical Law, Uppsala University and member of the Expert Group on Ethics, the Swedish Research Council.

Nils-Eric Sahlin, Professor of Medical Ethics, expert member Smer

Göran Solders, MD, PhD, Head of the Neurophysiology Clinic, Karolinska University Hospital

Juliet Tizzard, Head of policy and communications, Human Fertilisation and Embryology Authority

Hugh Whittall, Director, Nuffield Council on Bioethics