

This response was submitted to the call for evidence by the Nuffield Council on Bioethics on *Emerging techniques to prevent inherited mitochondrial disorders: ethical issues* between January 2012 and February 2012. The views expressed are solely those of the respondent(s) and not those of the Council.

Mr Roy Parkinson

I am a patient of Professor Turnbull's in Newcastle, and have been having treatment and attending his clinics for more than thirteen years now. He and his team are absolutely wonderful to us and we are extremely lucky to have a world leading professor and his team looking after us.

I know just how hard they all work towards trying to cure and eliminate Mitochondrial Disease and how difficult it is to find a cure for the patients who are suffering this debilitating disease.

I was one of the patients who went over to Dallas, Texas, in the collaboration between Newcastle and Prof. Tania Taivassalo in Dallas, I actually went over there five times, as part of their research and studies of Mitochondrial Disease.

I am writing to support the excellent breakthrough which Professor Turnbull and his team have discovered which will totally eradicate the suffering of thousands and thousands of people who would be subjected to a lifetime of suffering and pain with this debilitating disease for which there is no cure. At present, there is a high chance that the females would be passing this disease on to their children and the next generation and they also would be subjected to a lifetime of suffering and pain.

Now that a cure has been found, by preventing the transmission of Inherited Mitochondrial Disease, this should be a real celebration for all Mitochondrial Disease Patients who will know that they will not be passing on a lifetime of suffering to their children, and it would allow the children to use their own eggs to have a baby. Mitochondrial Disease would be eliminated completely. As a patient this is wonderful news.

Efforts to prevent the introduction of IVF on an ethical issue should be stopped immediately. The misguided principals of a few should not be allowed to condemn thousands and thousands of people to a lifetime of pain and suffering just to satisfy their own misguided ethical principals. Would they have objected to a cure for any other diseases which have a transfer of tissue from one human being to another such as Heart Transplants, Liver transplants, IVF and blood transfusion. All involve a transfer of tissue from one human being to another, so there should be no grounds for objection to In-vitro Fertilization (IVF) to prevent and to cure Inherited Mitochondrial Disorders.

Once again, this should be a real celebration for all Mitochondrial Disease Patients who will know that they will not be passing on a lifetime of suffering to their children, thanks to the discovery of a cure by these wonderful people.

I am fully in support of Professor Turnbull in his efforts to cure and eradicate Inherited Mitochondrial Disorders. Ethical issues should not be allowed to prevent or stop this marvelous medical advancement.