



Rt Hon. Andrew Lansley MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

19 April 2011

Dear Secretary of State,

Treatments to avoid transmission of mitochondrial disease

We are writing in strong support of the introduction of regulations to enable research techniques developed to prevent the hereditary transmission of mitochondrial disease to be used in clinical treatment.

We know that you have received a report from the Human Fertilisation and Embryology Authority (HFEA) providing an assessment of the safety and efficacy of techniques to avoid mitochondrial disease and that you will use this to inform your decision as to whether to proceed towards the introduction of regulations.

We note that the published report calls for additional experiments to be undertaken to further demonstrate the safety and efficacy of these techniques. We call on Government to publish a timetable for the introduction of regulations so that once sufficient pre-clinical evidence is established, clinical treatment is not unduly delayed. It is essential that if additional research is to attract funding, successful outcomes can be quickly introduced into the clinic.

Mutations in mitochondrial DNA can lead to people suffering disabling and potentially fatal symptoms including, blindness, organ failure, muscular weakness, learning disability and diabetes. Current research offers considerable promise to people who are at risk of passing serious mitochondrial disorders on to their children.

The UK's scientific leadership, financial investment and spirit of innovation have enabled work to progress to a stage where translating research into treatment looks achievable in the near future. Given the importance of such research for couples wishing to have children free of mitochondrial disease, and the speed at which research in the field is developing, researchers and patients now need assurance that such techniques will move into the clinic. We consider it essential that UK patients should benefit from treatments resulting from research conducted here.

The UK's legislative framework for human fertility and embryology research has enabled us to establish an international lead in these areas while ensuring that the highest standards of ethics, consent and patient protection are maintained. Currently, regulations are permissive in allowing research using 'permitted eggs' created from material provided by two women to address transmission of mitochondrial disease. Parliament had the foresight when revising the Human Fertilisation and Embryology Act in 2008 to anticipate advances in this field and, following significant debate, specifically included regulation making powers that would enable the use of new techniques in treatment.

We look forward to your response to this report.

Yours sincerely

**Professor Sir John Bell FRS HonFREng PMedSci
President
Academy of Medical Sciences**

**Lord Willis of Knaresborough
Chairman
Association of Medical Research Charities**

**Alastair Kent OBE
Chief Executive
Genetic Alliance UK**

**Sir John Savill FRSE FMedSci
Chief Executive
Medical Research Council**

**Robert Meadowcraft
Chief Executive
Muscular Dystrophy Campaign**

**Sarah Norcross
Director
Progress Educational Trust**

**Sir Mark Walport FMedSci
Director
Wellcome Trust**

**cc. Earl Howe
Anne Milton MP
David Willetts MP
Sir John Beddington
John Healey MP**