

## 2016 Update

### PEALS Symposium 2016

In June 2016 Erica and Ken organized and led a successful and well attended symposium as part of the International Association of Bioethics (IAB) World Congress, held in Edinburgh. The symposium: 'UK mitochondrial research and legislation: cutting edge or out on a limb?' addressed questions of what, empirically, other countries might learn from the UK's approval of human germline alteration in the context of mitochondrial disease interventions and, normatively, whether other countries should adopt the same or different policies.

Chaired by Simon Woods, the four papers presented in the symposium questioned the adequacy of the claims made during the UK debates; each highlighting different aspects of the proposed new technologies that aim to prevent the transmission of mitochondrial disease.

Erica Haimes presented work that she and Ken are conducting on the quality and tenor of the recent debates in the UK on legalising 'mitochondrial transfer' techniques. The presentation identified a number of socio-ethical issues that require clarification to ensure that other countries might have a more rounded debate before considering legislation.

Dr Cathy Herbrand, Senior Lecturer at de Montfort University, Leicester, and a member of the Belgian Advisory Committee on Bioethics, presented some of her research with families who are living with mitochondrial disease. She revealed that the rather simplistic public discourses around mitochondrial replacement were at odds with the complex reproductive choices faced by these families, for many of whom the technology remains inappropriate.

Dr Ilke Turkmendag, Lecturer in the Newcastle Law School, presented on her continuing work on the identification of gamete donors and the donor conceived child's 'right to know'. She noted that since donor conceived individuals can access identifying information about their genetic origins, individuals conceived from mitochondrial donation will be discriminated against as they will be denied such identifying information.

Ken Taylor presented the work of Dr Annelien Bredenoord, Associate Professor at the Julius Centre, Utrecht as she was unable to attend. Her paper concerned the recent advisory report on mitochondrial donation from the US National Academy of Sciences, highlighting the differences between the UK and US contexts and noting that the UK did not provide a simple model that the US could follow.

Professor Sheryl de Lacey, Flinders University, Adelaide, took the role of discussant, introducing a wider international flavour to the subject and reflecting on her role as a member of the two Australian National Health and Medical Research Council committees that are currently addressing mitochondrial transfer issues. This led the symposium into a wide-ranging, thoughtful and engaging discussion amongst those present. The subjects raised included questions about the level of detail publics should, and actually, have about these complex technologies, the speed with which the legislation was enacted in the UK, and the implications for the number of egg providers that will be required worldwide.

The symposium was described in the 'Key highlights and themes' section of the report on the Congress as

*'providing stimulating analysis of the challenges and opportunities in the regulations, and salient questions about the UK's legislative motive for this....[they] explored this topical area in an innovative*

*manner, providing new challenges to a debate that has seemingly been put to rest by many, and adding much needed analysis to the quiet that has ensued since the UK's regulations came into force'* (Dove et al, 2016:209).

Erica and Ken extend their thanks to the all the speakers and delegates for making the symposium such a success, and to the Wellcome Trust for providing the funding to enable it.