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Submission for: '**Senate Inquiry into mitochondrial donation and related matters**', **2018.**

I declare two reasons for my submission to this Inquiry:

1. I am a scientist who has worked in the field of mitochondrial disease. I graduated with a Bachelor of Science (University of Sydney), then a Doctorate in Biochemistry (La Trobe University). I then trained in medical research at the University of Otago Medical School, Christchurch NZ, Griffith University Brisbane, and am now employed at the University of Queensland. I specialised Biochemistry, working in pathology for 16 years at Guy's Hospital in London, and 13 years at Mater Hospital, Brisbane. I have published over 200 research and conference papers, of which many are concerned with mitochondria and inherited diseases that the chemical pathways (metabolism) in the body affecting cellular energy. Thus I have extensive intellectual and work experience in this matter.
2. I have served for the past 5 years on the Scientific Members' Advisory Panel of the Australian Mitochondrial Diseases Foundation (AMDF). Thus I have a professional interest in this matter.

During my many years of working in hospitals (I am now semi-retired), I have been privileged to witness tremendous advances in both the diagnosis and treatment of medical conditions in general, and inherited diseases specifically, including mitochondrial diseases. Many of these advances have been driven by the 'scientific revolution' in human genetics. By delving deep into the structure of the DNA or 'genetic code' of cells, we have come to better understand how our bodies function. This has also allowed us to understand how damaged genes cause diseases, and it has provided new clues on how we may treat these diseases.

At Guy's Hospital in London, I was privileged also to work alongside clinicians and scientists who were in the forefront of the medical technology of organ transplantation: kidneys, hearts, then livers and lungs, as well as corneas, skin etc. Bone marrow transplantation was originally developed to treat leukemias. Kidney, liver, and bone marrow transplantations were later utilised to treat inherited (i.e. family) diseases that can affect our body's chemical pathways. These are called 'metabolic diseases', and typically have caused slow and painful deaths for babies and children but are now increasingly treatable.

In addition to transplantation we also learned how to give parents, who were carrying damaged genes that previously killed their children, the chance to have healthy children. These were the new medical technologies of 'pre-natal diagnosis' and 'in vitro fertilisation' that identified and selected against the damaged genes. I met many parents who had seen their child (or several children) die of genetic disease and had given up hope of having a family but were then able to have a healthy son or daughter as a result of these new medical technologies.

Mitochondrial diseases are common and deadly but have defeated these efforts to provide 'in vitro fertilisation' for afflicted families. This is because mitochondria, the energy centres in our cells, carry their own genes that come only from the mother. This unique problem with mitochondrial disease has now been brilliantly overcome by the medical technology of 'mitochondrial donation.'

Ethically, this is not different from organ donation or 'in vitro fertilisation.' However, the popular press has produced the term "three-parent babies" (e.g. The Sun, UK, 16 Mar 2017; ABC News, 19 Nov 2017) *versus* the less emotional "three-person babies" (BBC News, 2 Feb 2018). We need to remember when heart transplants were first conducted in 1967, that:

"In people's minds this organ was endowed with almost mystical qualities—it was the seat of love and other emotions… Its transfer from one person to another was regarded as an unnatural act, meddling with "personhood" and trespassing into territory that had a spiritual quality." (Dr R. Hoffenberg, British Medical Journal, 2001, vol. 323(7327), pp.1478–1480; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1121917/).

There are of course various ethical and legal issues such as "the right to know" of donors and recipients etc: these are not insurmountable. I respectfully suggest that rather than 're-inventing the wheel', the Australian Parliament could review the UK requirements for ethics, safety and efficacy of 'mitochondrial donation' prior to legalisation there – unlike the USA where debate by its lawmakers has been influenced by superstition and religious prejudice, to the extent that many medical technologies have been denied.

In conclusion, I respectfully suggest that the Senate views 'mitochondrial donation' as simply an extension of medical technologies such as blood transfusion, transplantation and 'in vitro fertilisation', which have been helping our citizens for decades. Many thousands of Australians have benefitted from donated hearts, kidneys and corneas. Aussie families have been blessed with children from 'in vitro fertilisation.' Long ago, we welcomed technologies such as kidney dialysis or the heart-lung bypass as ground-breaking methods for saving lives. 'Mitochondrial donation' is no more "unnatural" than a blood transfusion, where we might say the recipient's life is blessed by "the blood of a stranger." I respectfully recommend that the Senate views 'mitochondrial donation' with an open mind. It is not an attempt to "play God" but is simply part of a long line of medical technologies, aimed at saving lives.

Your faithfully,

Dr John A. Duley

3 April 2018