

Submission to Senate Inquiry Into Mitochondrial Donation

03/05/2018

I wish to express my support for the Australian Mitochondrial Disease Foundation in their desire to have the Australian Government approve the procedure known as Mitochondrial Donation. This procedure is being used in other jurisdictions around the World to help stop future generations from passing the disease on to their children.

My interest in this disease was brought about when my son was diagnosed with the disease at about age 22 years. He is now age 40 years and the disease is slowly affecting his ability to cope with everyday living. At age 22 when he was first diagnosed with the disease he had a double chamber pace maker fitted to his heart. Since then the disease has been gradually affecting his health in areas such as hearing and eye sight. He now requires hearing aids and regular eye testing. He is at the stage where he has very poor vision in one eye and needs glasses to help with his sight. It is affecting his balance and he is reluctant to negotiate stairways etc. He has also been told he is on the verge of being affected with diabetes but is trying to avoid it with healthy diet and exercise. All brought about by mitochondrial disease. Although he tries to stay positive I can see at times that he has his down moments trying to cope with daily life. Unfortunately there is no known cure for this disease and no way of knowing what further health implications may arise for him in the future.

Having read a lot about the pros and cons for mitochondrial

donation I have come to the conclusion that if managed in a professional and ethical manner then the procedure is safe and has the potential to prevent further generations being born with the disease. This has obvious advantages to the individual who is then able to live a normal healthy life compared to living with the disease.

I am aware there is research being done both here in Australia and overseas in trying to find a cure for this disease. I would encourage the Australian Government to continue to support the researchers in any way possible to hopefully one day find a treatment that would benefit those individuals who suffer with mitochondrial disease. I would also like to see the Government acknowledge to the mitochondrial disease community that they are aware of the daily grind and suffering that sufferers go through and that the Government are taking their concerns seriously and working towards a successful outcome for all concerned.

I would like to thank the Senators involved in this inquiry for allowing me the opportunity to express my support for the Australian Mitochondrial Disease Foundations' request to allow the Mitochondrial Donation procedure to be accepted as a way for health professionals to help combat this disease.

Yours Faithfully