7th May 2018

Committee Secretary
Senate Community Affairs Committee
Via email community.affairs.sen@aph.gov.au

Re: Mitochondrial Donation

My name is [redacted] and I suffer from a genetically inherited disease named Mitochondrial Encephalomyopathy Lactic Acidosis and Stroke Like Episodes (MELAS). The reason I am providing this submission is to share the current impact of Mitochondrial Disease on myself and my family in the hope that Mitochondrial Donation will be introduced in Australia.

I am now aware that for several generations at least, my family has been affected by mitochondrial disease, which started with my grandmother, [redacted], who became unwell in her late fifties. She suffered from degenerative hearing loss and suffered from stroke like episodes, poor balance, night twitches and fatigue. After becoming progressively unwell, [redacted] died aged 70 years, after suffering for 20 years.

My family then noticed similar symptoms starting with my mother [redacted], who started to lose her hearing from about the age of forty. She wore hearing aids, and her balance was affected. She suffered from fatigue. We also saw similar issues with my maternal aunt and her daughter.

Whilst we knew something was wrong, we didn't know what it was. At the age of 34, my brother [redacted], who otherwise seemed fit and healthy, was rushed to hospital with what was thought to be a stroke. The tests, however, suggested it wasn't a traditional stroke, and a review of our family history led fairly quickly to a diagnosis of a Mitochondrial Disease - this was the first we'd ever heard of the term.

My mother, my siblings and I then also tested positive to the same genetic changes in our mitochondrial DNA. Finally, this seemed to explain the mystery surrounding the health issues faced by many members of my family - but our story was only really beginning.

Following his first acute episode, my brother [redacted] health slowly deteriorated - he suffered more mitochondrial strokes, seizures, he went deaf, he developed tonsil cancer, lost his balance until he was no longer able to work – with several hospital stays along the way. No longer able to drive, [redacted] became more and more socially isolated and his ill health took its toll on his family with his marriage eventually breaking down.

Separating from his wife, he returned to live with my elderly parents. This was just under 11 years after his first mitochondrial stroke. It was about six months later that on a routine check-up, [redacted] specialists detected what they thought was the precursor to another acute episode and he was admitted to hospital. This was a very confusing time for us all and things went downhill quickly with [redacted] being admitted to ICU. Within two weeks, with his 13 year

old son and 11 year old daughter at his side, we watched helplessly as my big brother [redacted] passed away, aged 44 years.

Over the few years before [redacted] death, mum's health was rapidly declining. She too started suffering from mitochondrial strokes and each time took longer to bounce back. After several extended stays in hospital, and about two years after [redacted], mitochondrial disease also took mum's life away.

Which brings my journey to me. I am a mother of two daughters, [redacted] aged 18 and [redacted] aged 17. I am currently studying a degree in Visual Arts at [redacted] University on a part time basis, and I also work as a contract draftsperson. I am quite a busy person, but I am also pretty much exhausted most of the time. I keep myself busy in the fear that if I slow down, my body will give in to Mitochondrial Disease.

I am aged 52 years, and in my late forties, and just like my mother, I started to lose my hearing. I now wear hearing aids which do help to some extent. But at the end of a long day when I am really tired, I find even the hearing aids don't work.

I catch up on sleep during university breaks, where I tend to have an afternoon nap every day – only they are not really naps, they are like a two, three, sometimes even four hour sleeps. Life is a bit of a struggle. It is hard for friends to understand my condition and I sometimes isolate myself because it is just easier to do so. I'm a very social person, but I find myself withdrawing because it is all getting too hard with the hearing loss and lack of energy. Having the same symptoms as my brother, mother and grandmother, I have a not so pleasant vision of what lies ahead.

I worry for my daughters, as they too will have the same genetic mutation. What does the future hold for them? Will they too pass on this horrible, debilitating disease to their children? Every time one of my children get sick, I am forever questioning if this is a normal illness or is it a symptom of Mitochondrial Disease.

As there no cure for Mitochondrial Disease, the introduction of Mitochondrial Donation in the UK has given worldwide sufferers hope, something they haven't had before. A big black cloud that has been hanging over my family for years is slowly starting to dissipate. If this technology was available when I was having my children, I most certainly would have used it and I will be strongly encouraging my daughters, [redacted] and [redacted], to consider Mitochondrial Donation if ever they decide to start a family.

I would like to see the outcome of the Senate Community Affairs References Committee Inquiry result in Mitochondrial Donation being introduced in Australia, as this would mean the eradication of such a debilitating disease from our family, giving future generations the chance to lead happy and healthy lives, and not suffer long, slow deaths as previous generations before me have.

Thank you for your consideration and all the work you are putting in to an issue that I care about deeply.

Kind regards,