

This response was submitted to the call for evidence by the Nuffield Council on Bioethics on *Emerging techniques to prevent inherited mitochondrial disorders: ethical issues* between January 2012 and February 2012. The views expressed are solely those of the respondent(s) and not those of the Council.

### **Alicea Baldwin**

1. I am a 38 year old female who was told she had a mitochondrial disorder about 3 year ago, so far my symptoms are diabetic and inject 4 times daily this was diagnosed 8 years ago threw pregnancy, it was later realised it was part of the mitochondrial disorder, my blood levels are very up and down I am not over weight smoke or drink. I am 40% deaf and have to wear an earring aid in both ears. I also have pigmentation at the back of my eyes which is monitored closely. So far this hasn't effected my eye sight. My heart is also closely monitored in case of any defects these are just what I know at the moment are part of my mitochondrial mutation I live in West Yorkshire so its a 5hrs round trip to visit Newcastle hospital which is the nearest hospital to me which deals with mitochondrial.

2. My mutation was passed on to me maternally by my mothers side of the family meaning the females are the carries and can pass it on to the next generation. I have 2 beautiful daughters who are aged 8 & 4. What does this mean to them what have I passed onto them and what will they pass on to their future generateration.

3. This is where I feel really strongly I believe in God & attended the Salvation army for 16 years of my life, I would never condemn a life to be taken, but we are talking about some thing which as no feelings, no physical body, no taste, no touch. If I thought for one minute that these researches can wipe out the mitochondrial in my family or anyone else's. I would do it in an instant when you have your own flesh & blood involved you want them to be healthy and live a fuller life as possible. I would go to the ends of the earth if there was a chance that I haven't put my children at risk & them to their un born so yes I would most definitely go aboard for the treatment & would be behind my children 100%. if they wished to do so.

4. I would like to think I have always been bought up in a trusting and loving family and the same to my children I would have no worries in telling them, or an unborn child when it came in to the world and was old enough to understand, that these techniques have been used surely it would be better for us to say we tried everything we could in our power to give you the best start possible rather than we did nothing.

5. I know everyone as very different views on how medical science is moving on but surely if God didn't want it to move on he wouldn't give us the expertise & equipment to do so. How many of these people who object actually have someone this involves( their own flesh and blood), would they still leave well alone if it was there daughter, your options change on things when you become a mum and when its you they talking about what it concerns.

6. I give it all 100% backing & only hope it not too late for my grandchildren and so on & Thank God that there may be a cure to all these horrible dieses and give everyone a fair chance in life surely we all deserves that.