

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.

Valerie Thomas

I agree with the ongoing research into Mitochondrial disorders. As the female line (including myself) within my family has been affected with MERFF. This cruel illness affects us on a daily basis in a number of ways:-

- Severe fatigue
- Joint pain
- Muscle spasms
- Pains in all joints
- Continually growing unsightly/painful Lipomas
- Heart problems
- Eye problems
- Speech problems
- Hearing problems
- Cognitive problems

I would like to highlight my families experiences of living with defective mitochondria. Unfortunately we did not know that we had this condition until my children and Grandchildren had been born. My mother and sisters were all wrongly diagnosed resulting in more family members being born to this condition unknowingly.

I was diagnosed through Dr A Clarke approximately eight years ago this resulted in myself and sisters being referred to Prof. Turnbull, as this condition is so rare we have to travel to Newcastle for annual check ups. Sadly, my mother and one of my sisters had already passed away as a result of this condition.

My hope is that the ongoing research into these conditions could help the future's of my Daughters/Granddaughters, any future Grandchildren/Great Grandchildren and any other person's affected. If there is a possibility of stopping this cruel disease through egg research I feel this is the way forward as I believe everybody deserve the right to a healthy life.