

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.

Mrs Sylvia Halliday

EMERGING TECHNIQUES TO PREVENT MITOCHONDRIAL DISORDERS
WRITTEN SUBMISSION - ETHICAL ISSUES -

1. I HAVE BEEN DIAGNOSED AS HAVING MITOCHONDRIAL MYOPATHY.
I WILL BE 66 YEARS OF AGE THIS YEAR 2012.
2. RESEARCH INTO REPLACING DEFECTIVE MITOCHONDRIAL DNA IN A HUMAN EMBRYO MUST BE A GOOD THING IF SAFE AND EFFECTIVE TECHNOLOGY PREVENTS TRANSMISSION OF INHERITED MITOCHONDRIAL DISORDERS TO FUTURE GENERATIONS. THUS ALLEVIATING MUCH SUFFERING/STRESS AND COST TO HEALTH SERVICES!
3. FOR THE GENERAL PUBLIC TO UNDERSTAND HOW VITAL THE RESEARCH IS. THEY NEED AND MUST BE INFORMED ABOUT MITOCHONDRIAL DISORDERS FOR THEM TO REALIZE THE FULL IMPLICATIONS OF CARRYING AND LIVING WITH DEFECTIVE MITOCHONDRIA. THERE IS MUCH MISUNDERSTANDING AND IGNORANCE AND MANY PEOPLE HAVEN'T EVEN HEARD OF THE CONDITION. ONCE THE PUBLIC IN GENERAL ARE AWARE OF THE VAST ARRAY OF DEBILITATING SYMPTOMS AND STRESS/ANXIETY ENDURED BY SUFFERERS/CARERS/FAMILY AND FRIENDS; I HOPE THAT MANY WHO ARE AT PRESENT 'OPPOSED' WILL CHANGE THEIR MINDS, AS AT THE PRESENT TIME 'IGNORANCE IS BLISS'. ATTITUDES NEED TO BE CHANGED TOWARDS THIS GENETIC DISEASE!!