Ethical and Social Policy Considerations of Novel Techniques for Prevention of Maternal Transmission of Mitochondrial DNA Diseases

Heather Ward, PhD
Patient Representative
My Story with MELAS

• Something was not right…
  – Track at age 15 years
  – My grandmother: at 61 years old died a terrible death
  – My mother: stroke at age 40, dementia, hearing loss
  – My daughter’s 18 month birthday

• Since the diagnosis
  – Birth of my son, Matthew, IVF with PGD
  – My uncle: Died at 52 of cortical and basal ganglia calcification, dementia began at 12 years old, uncontrollable diabetes and deafness, in a wheel chair at 40
My Belief

“If you always do what you’ve always done, you will get what you always got.

- Albert Einstein
Benefits of mDNA Replacement Therapy

- Allows females like my daughter the opportunity to have children with their nuclear DNA
- Decreases the incidence of terrible, neurodegenerative mitochondrial diseases
- Decrease the number of hospital visits and hospital costs associated with treating patients with mitochondrial disease

We Create Medicines for Patients with Diseases…. Why Wouldn’t We Create a “Cure” for Future Children Who Would Otherwise Suffer from a Disease where there is NO Treatment?
Frequent Ethical Questions/Topics in the Literature: 
**My Perspective**

- Does manipulation of mitochondrial DNA allow people to design babies to their specifications?

- Why can’t women with mitochondrial diseases use egg donors or adopt?

- Are there ethical/social issues if a child is born with donated mitochondrial DNA from one individual and nuclear DNA from another individual?
  - Identity, parenthood rights/responsibilities, ancestry

- Does MRT potentially “cure” a child who would otherwise be born with mitochondrial disease or does it introduce genetic alterations such that a different child is created?
Frequent Ethical Questions/Topics in the Literature: My Perspective

• My view on the ethical issues associated with novel/uncertain first-in-human applications including health risks, assessment of benefit to risk, can consent be “informed consent”.

• My view on the moral status of human tissue (manipulation and/or destruction of embryos).

• Could the availability of MRT create a sense of obligation for families at-risk for genetic disease to reproduce only with the help of advanced technologies?

• Could the availability of MRT affect how people born with mitochondrial disease are viewed in society?

• Fairness, equity, and access: health equity/access issues to IVF / MRT, donated eggs.
UNLESS someone like you cares a whole awful lot, nothing is going to get better. It’s not.

—The Lorax

THANK YOU!