

TECHNIQUES TO PREVENT INHERITED MITOCHONDRIAL DISORDERS : ETHICAL ISSUES

1. **Laura's Story- Brief description of a young woman with MELAS.**
2. **Professor Turnbull & team in Newcastle – not just Scientists but Doctors who try to help.**
3. **Ethical Issues – one parent's view.**
4. **Appeal to committee.**

1.1 Laura is 29. Laura has MELAS. I am Laura's Mum and I am writing her story because she can no longer write or spell. I don't seek sympathy. I merely want to show how one beautiful young woman and her family are affected by this deadly disease.

1.2 Laura is our first born, a bright bubbly toddler, a lively fun loving articulate, literate teenager who loved dance and drama and who dreamed of a career on the stage.

1.3 Laura had her first seizure at 14, her first "stroke like" episode at 21- that was when the big black cloud that is MELAS descended on our lives. She now has seizures on a daily basis. Her brain is badly scarred and dementia is setting in. She struggles to find words, repeats phrases over and over again, and has difficulty reasoning and understanding simple concepts. Laura also has profound hearing loss, bowel and muscle problems, and very little energy. Her independence is gone and she gets angry, frustrated and depressed. She still dreams of finding a boyfriend, getting married and having children.

1.4 Our other daughter has MELAS too. So far she is symptom free. She has watched her sister deteriorate and suffer and knows the possible implications for herself and any children of her own. She may decide to remain childless.

1.5 It's too late for our daughter, but for all the "Lauras" of tomorrow and for her wonderful caring sister, PLEASE give this incredible technique a chance.

2.1 Professor Turnbull and his team are not merely scientists. They are not seeking fame and kudos for their work. They are doctors who actually care about people, they devote time to patients and their families in clinics and in hospitals as well as spending hours in the lab trying to develop these techniques. They have been given these amazing skills and knowledge and are not trying to create "perfect people", they are solely trying to eliminate these fatal diseases.

3.1 I am not a scientist. I understand the techniques involved in trying to prevent the transmission of mitochondrial disorders and, for me, although it is obviously difficult to be objective since I am living with MELAS, surely the benefits of this procedure far outweigh the concerns raised by those who are so strongly opposed to it.

3.2 Is this technique more unethical than IVF by a donor for infertile couples or more unethical than surrogacy? I don't believe so.

3.3 If I had known 30 years ago that my children would inherit a fatal disease would I have chosen to remain childless? I can't honestly say. If I had been told that there was a treatment available that would enable them to be free from mitochondrial diseases and their horrific symptoms would I have opted for that? Definitely.

4.1 I would like to appeal strongly to the Bioethics Committee not to dismiss this wonderful development in the eradication of mitochondrial disorders and to give hope to future generations so that these diseases, which are like a death sentence being given to innocent people, can some day be a thing of the past.