

Education.....page 12

- In New Zealand the Mental Health Foundation advertisements featuring much-loved rugby great, John Kirwan openly speaking about his depression, has had wide success in the acceptance of depression, the reduction of discrimination against sufferers and bringing it out into the open. He is a very successful man without any arrogance, a family man and someone who people look up to. I would appreciate consideration of a similar advertising campaign, with a similar **worthy champion, to “normalise” the donor conception community and create better understanding.** It is easier to relate to, and empathise with, when faced with real people.
- I believe much could happen at conferences of, for instance, the Royal Australia and New Zealand College of Obstetricians and Gynaecologists. All it takes is a **charismatic doctor with passion and feeling for these donor conceived people to lead the way and change the culture,** make it cool to be up front and try and right the wrongs of the past. Make it cool to get the grass roots sorted out. **Conferences are great forums for change.**

Tagging and Tracking Protocol of Donor Sperm, Eggs and Embryos worldwidepage 13

- All facilities involved in Donor Conception and Assisted Human Reproduction and Research should by law be required to do an **annual stock take of all sperm, eggs and embryos** held, whether donor or otherwise, for the national register. This is some of the most important stored material on earth and should have proper accountability systems. I feel as momentum for all this technology took off basic housekeeping was overlooked. This material is so precious. It has a power beyond any of those involved in the industry, the power to create life. If huge supermarkets have systems to manage annual stock takes for the tax department, why wouldn't the doctors, scientists and businessmen involved in this industry be required to have such checks and balances?

How long should donor sperm, eggs or embryos be stored?page 16

- **At the time of signing sperm, eggs or embryos over to be stored,** for say five years, the **parties should clearly state** that they want this material to be destroyed at the end of this time, or otherwise give permission for it to be either donated to other people wanting children, or

used in research. The right to contact the clinic during that time to alter that decision should remain and, naturally new forms completed. The clinic/research facility should not have to chase up their clients/patients when the five years are up.

- I believe there needs to be a **national protocol, set up in conjunction with medical ethics experts, for destroying of sperm, eggs and embryos**. This is to ensure that there is respect (many cultures demand this) in the process and that there is signed off proof that the material has in fact been destroyed according to agreed convention, and not used for something else. Again, for transparency, I believe that three people should sign this off, just as it should happen when the material is received by a clinic/research facility.

Consumer Guarantees Act

When I was told at the clinic that they only use five families for each donor's sperm, and that I was the last, **I was told a lie**. Whether it was advertent or inadvertent is not even relevant. **Any other industry in New Zealand, under the Consumer Guarantees Act, would not get away with such misrepresentation of a sale or service**, for whatever reason, be it poor record keeping or failing to strive for excellence in all aspects of the business. So, how, when this involves something more important than anything else that is for sale or service, are there no consequences for the clinic? It is wrong, so wrong.

What comes to mind is the secrecy and lack of accountability which has enabled some clergy to go without consequences to their unacceptable behaviour which has brought lifelong pain to so many children. **It does not happen when proper processes, transparency, respect and reverence are in place. My daughter too suffers pain.**

"Left over" embryos from an IVF clinic

A couple of weeks ago, while watching the news reporting on the first human embryonic stem cell trial I was startled to hear the news reader flippantly announce that the "*stem cells were harvested from **leftover embryos from fertility clinics***". This is just a symptom of the lack of respect and reverence given this material and those who donate. If people choose to donate this material to research the very least that should happen is that their contribution is acknowledged and honoured. (ie words to the effect "*we acknowledge the generosity of a couple who after undergoing IVF treatment donated the embryo and made this possible*". It is an ethos that is not difficult to achieve, even anonymously.

I mention this because **ultimately the whole attitude surrounding this culture of secrecy and lack of respect does affect those who are born as a result of**

donor conception. Yeah, **“left over”** dinner – for lunch next day. Is that the best that these scientists at the forefront of research can do in their press releases? It would not take a rocket scientist to bring more grace and reverence to all this. I am not religious but I do like an ethos of honour and respect.

Postscript

The sibling that my daughter was seeking has also been adversely affected by finding out she is part of a tribe (of 19). Subsequently she has withdrawn her interest in sharing information. While we absolutely honour and support her decision, as we want the very best for her, it will be another blow for my daughter.

I wonder if those who perpetuated this secret culture have ever stopped to imagine some of the consequences, if it were their own family. **Perhaps they need to look into the eyes of some of these donor conceived people, and stop to listen, to care, to promise to do everything to sort it out.**

I do acknowledge that there are many in the industry who are doing their very best and I thank them so much for that. They must put pressure on those who are not.

Parents

I have not mentioned the **effects on the parents of the donor children** who are experiencing the secrecy and surprises. I would ask you to imagine for a moment the deep pain and disruption of lives, of the other members of the families watching their precious loved ones come up against it.

I thank you for the opportunity to submit and thank you to all those who had the foresight to make this inquiry happen.