Submission No 23

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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Fertility
EAST
Assisted Conception Clinic

SUBMISSION TO THE LEGISLATIVE ASSEMBLY COMMITTEE ON LAW AND SAFTEY

The management of information related to donor conception in NSW

Terms of Reference

a) Whether people conceived by donor conception prior to January 2010 should have access to donor conception information, including information that identifies their donor and donor conceived siblings

b) Which agency should manage donor conception information and provide services related to the release of this information.

c) What counselling or support services and public education measures are necessary to support people who are seeking access to donor conception information.

d) Any other relevant matter.

Thank you for the opportunity to provide this submission.

Introduction

Fertility East is an Assisted Conception Clinic situated in Bondi Junction which has a non-discriminatory treatment policy and provides fertility treatment to women and couples to achieve pregnancy through treatments which include IUI, IVF, ICSI, with or without donor gametes. Our core philosophy is that no woman should be denied the right to have a child of her own. We have a strong ‘We Care’ program that applies to our patients, our staff and impacts on the greater community.

Fertility East was founded in 2007 by Fertility Australia Pty Ltd. Fertility East is a completely new clinic. IVF NSW functioned as a fertility clinic in Bondi Junction. IVF NSW closed in 2006 and under current RTAC guidelines was obliged to get another clinic to take over the management of any gametes or embryos that were collected by them. Fertility East voluntarily took over this obligation. The state of IVF NSW records and samples were incomplete and so while attempting to fulfil the RTAC obligation wish to point out that Fertility East cannot be held liable for any incomplete or missing documentation pertaining to these patients.

Terms of Reference

a) Whether people conceived by donor conception prior to January 2010 should have access to donor conception information, including information that identifies their donor and donor conceived siblings

The question should in fact read adults rather than people as the current NSW ART Act 2007 provides information to donor conceived offspring from the age of 18 years which is appropriate, and so "Should donor-conceived adults have retrospective access to donors identifying details?" is very easy question to answer.

Fertility East feels very strongly that no information about any donors, donor conception, nor donor conceived siblings ever be released retrospectively, except via the NSW current voluntary donor registry.

This opinion is based on several reasons:

1. A foundation of the ethical basis of medicine and the patient doctor relationship is the maintenance of confidential information and privacy even if this was not enshrined in law.
2. Retrospective legislation breaking this basic rule of law and medicine would have a devastating prospective effect on every aspect of medicine as patients could no longer trust their confidential medical information to doctors in case the government made this available to all. By the same token this concept could be extrapolated to every branch of human endevour with untold consequences.
3. Should the State Government proceed with this retrospective process, it would contradict current ethical thinking as it would represent an attempt to service one very small section of the community and place their needs, above the common good and would represent an abhorrent abuse of authority and should not be pursued.

b) Which agency should manage donor conception information and provide services related to the release of this information.

c) What counselling or support services and public education measures are necessary to support people who are seeking access to donor conception information.

d) Any other relevant matter.

"If retrospective access were granted what conditions should apply, a summary of points b,c and d ?"

This is a rhetorical question as outlined below:

If this were to happen, a number of problems would need to be solved and conditions applied, including but not limited to:

- How can one initiate contact with anonymous donors in a way that does not jeopardise their anonimity, Impossible except by promoting a voluntary donor register? Jeoparising the donor's anonymity can extend to his family, his offspring with a spouse and any other donor conceived offspring who may or may not be aware of their origin. Thus giving donor conceived offspring access to the donor information could be giving them directly or indirectly access far beyond the extent of the donor especially with the availability of social networking systems.
- No information should be released without the consent of the donor who if eventually contacted should always have the final say.
- Provided donor consent is available, only information that can be retrieved can be released, and many records are missing or incomplete, not to mention may be overseas.
- Only information relating to an enquiry may be called for.
- If donor contact is established, there must be a 12 month cooling off period.
- All parties must receive the appropriate counselling and preparation for an introduction, which superficially sounds altruistic but practically is almost impossible to achieve, not to mentioning the cost to the state which they would unlikely be able to afford.

"What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required?"

Retrospective access raises many contentious issues.

- Liability if one releases confidential information without the donor's consent. The reason for the release of this information is based on the desire of a donor conceived child and not to assist the government in ensuring state security or combating or dealing with a criminal event such as murder which may justify such an action.
- Retrospectively changing the law about identification will null and void any assurance we can give to prospective donors that we, as legislative bound units, can ensure that their wishes and requests are respected and the law adhered to.
- A secondary but vitally important impact of retrospective legislation and government involvement in reproduction is to further diminish our very limited supply of NSW

donors by creating more doubt about their confidential information. The irony is that the harder the law makes if for patients to use donor sperm, provided legally by appropriate clinics, as well as the further reduction in available donors, the more the patients will seek finding their own donors i.e. non controlled reproduction with all its pitfalls and this is a perfectly legal approach! This effect negates the very basis of the ART ACT 2007.

- The release of private and confidential information would open the NSW government up to litigation such as in Europe where S.H and Others took Austria to the European Court of Human Rights and initially won their case but the case continued for more than 15 years in court.[i] The comments on the retrial reversal condemned the court on making a judgment based on a technicality and not on a clinical or moral basis.
- The process of applying for information would have to be managed and funded by the NSW department of Health or other such governing body. An individual would need to apply to a governing body to retrieve information and the individual must pay for the service.
- It is imperative that all parties attend extensive implications counselling by an ANZICA qualified counsellor to ensure that the expectations of all individuals is managed and that all parties have a proven and known support network of qualified professionals to assist them in the event that the meeting is not a positive one.

a) Which agency should manage donor conception information and provide services related to the release of this information.

As the NSW Dept of Health has set up the systems for record management and the voluntary register, it makes sense that this government body continues to provide this service. Instead of creating a whole new service and management system, we recommend that a large amount of funding be allocated to the expansion and development of the systems that are already in place i.e. the voluntary donor register and the post 2010 NSW donor register.

The often quoted statement that anonymous donors require family information regarding health issues is of minimal importance as the incidence of genetic and other diseases is so infrequent that it seldom presents in a family and is usually detected by genetic or other testing.

Instead of embarking on the path of retrospective legislation it would be far more suitable to promote the excellent system we have. If an anonymous donor wishes to be contacted then by educating him, and reminding him regularly it would solve most problems without all the potential financial social emotional and legal consequences that could ensue.

"Should another standalone body be established to manage the register? What other areas could it have responsibility for?"

It would be a waste of money to establish another body to manage the register, so either the NSW Department of Health or the FSA could be given funding to manage the information. The body could have responsibility for records management, managing requests, liaising with clinics to retrieve information, coordinate the counselling services and processing payments from individuals.

a) What counselling or support services and public education measures are necessary to support people who are seeking access to donor conception information.

"Should counselling and support services be offered to those seeking donor conception information from the donor register?"

There should be mandatory counselling support services made available to all people who are seeking access to donor conception information, wether this is available or not.

The real question is whether the NSW government has the financial, medical, social and legal resources to provide the type of service needed, when so many aspects of the current health system are in desperate need for funding, not to mention facilities with far more pressing social issues such as mental institutions, surgical waiting lists, dental problems etc.? Again the needs of the many outweigh the needs of the few.

Public education needs to be improved by way of broad advertising to communicate changes to the legislation and what information will become available to all stakeholders. This point is geared towards only one stakeholder in this whole scenario – the children. There are so many more stakeholders that this involves:

- The donors, and their families
- The clinics where the donors donated
- The clinics who currently hold the records of those donors
- The recipients who underwent the treatment
- The children born from the donation and the treatment

If this service is going to be made available to the offspring it should be made available to the donors who's information is going to be released without their knowledge.

Note that the so called rights of the child also extends to the hundreds of unkown children born from donor conception, and by formally or accidentally revealing this knowledge to them could have devastating effects on not only them, but other siblings, parents and families, a cascade effect the proportions of which cannot be quantified

“Are there any other types of support that could be offered?”

There could possibly be support groups established to help those who are unable to obtain any information better cope with their disappointment. It is very important to manage these donor conceived individual’s expectations.

“How would support services be funded? By the government, the individual seeking the service or by ART clinics?”

These services would be entirely ‘user pays’. There is no way an ART clinic should be required to provide such a service. The ART clinics and doctors acted according to the laws of the time and if the Government wishes to change the law retrospectively the Government must pay the price.

“How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a stand alone body?”

These individuals should be referred to these services by the body that is put in charge of this register. The NSW Department of Health should have a list of qualified counsellors who are able to handle each case and meet with all parties prior to an introduction. The donor would need extensive counselling at the expense of the individual if an introduction was ever to occur.

“How long should ART clinics be required to retain records?”

There is no specific legislation regarding pre 2010 donor records so to impose a limit when most records probably would have been destroyed, are incomplete or missing is a bit like closing the stable door after the horse has bolted.

“What should happen to records if a clinic closes?”

This has already been dealt with by RTAC guidelines

“How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with,”

As with the RTAC and NATA regulations, clinics are required to maintain accurate records. However, a clinic which inherited some but not all records of previous donors and patients can not be held accountable if the records are not available from prior to the founding of the current clinic .

Recommendations

1. **Under no circumstances should the law be changed retrospectively**
2. **The Victorian legislation (which requires prospective IVF patients to have police clearance before treatment to mention on aspect) should not be upheld as a model of common sense for the common good but rather something, which is reviled by both local and international legal, medical and ethical bodies.**
3. **The only logical approach is to pursue what the state government originally did and that is an opt in system ie voluntary donor register which has already been created but not really promoted to the general public. This is the cheapest, easiest and most legitimate, cost effective option. If the current government has failed to adequately promote such a cheap and effective system, what are the chances of providing and maintaining a far most costly and complex system?**
4. **The absence of so many old records means that for many patients the system is doomed to fail before it begins.**
5. **Staff requirements would include a medically trained person to understand the specific donor process that was involved. A legal person to find the way through privacy medical records if they exist. Psychologist/counsellor ANZICA registered and staff to track missing details and office staff to do the leg work. This would be the basics, dependent upon how many requests they would get.**
6. **There has not been any mention in the submission, of the parents of these donor conceived children whose free choice it was to pursue this option. Before making any decisions they too, have a responsibility for the current situation, and their role and responsibility needs to be taken into account.**
7. **One must query the validity of interpreting these submissions as there cannot be sufficient proof that the anonymous stakeholders I.e. the anonymous donors , who were assured of anonymity by law, would now wish to come forward.**

Yours sincerely,

Dr Joel Bernstein

Medical Director Fertility East.

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[i] Wannes Van Hoof, Guido Pennings: ‘The consequences of S.H and Others v. Austria for legislation on gamete donation in Europe: an ethical analysis of the European Court of Human Rights judgments’ – Reproductive BioMedicine online (2012) 25, 665-669