Meeting to discuss the consultation of the guidelines review with

Fertility Plus – Auckland

Tuesday 24 October 2017

Proposal 1

Overall, Fertility Plus supports rescinding the biological link but notes that they have only seen a handful of situations through their clinic that would benefit from the biological link being removed.

Those present noted:

- the increased complexity of relationships for families and resulting children that these changes could create,
- counselling sessions would need to account for this increased complexity so that Fertility Plus could support ECART in submitting a comprehensive account of the counselling sessions
- consent forms would need to be amended,
- removing the biological link policy is analogous to an adoption situation with respect to genetics of the child only,
- Discussion about the definition of biological versus gestation

Proposal 2

Fertility Plus agrees with the idea of strengthening access to one's cultural and biological history. The creation of individuals is becoming more complex and there is a need to strengthen information available to those conceived through ART.

Queried the idea that putting an obvious insert into an individual's birth certificate may not be appropriate, given that individuals often need to provide their birth certificate in certain situations such as enrolling in school, and it could be thought of as a breach of that individual's privacy, when they are not able to access further information themselves until they are 18 years old.

Idea that anything on a birth certificate signalling more information is available should be a small annotation. Advantages of possibly prompting parents to be more open to their ART conceived offspring as a default which is viewed as a good thing.

Queried the administrative burden if birth certificates were amended and if it was retrospective in terms of the clinic having to contact people to let them know that the birth certificate will be amended.

Brief discussion about the need for more research into this area to explore outcomes for children.

Proposal 3

Overall this proposal makes sense. Fertility Plus noted that it would be helpful to have guidance on where Fertility staff need to look in the new guidelines to make sure that everything is ticked off for a strong application/to protect patients.

Suggested that a table or diagram would be helpful, scenario by scenario, that may help to guide the application process. In the event of a specific situation, Fertility staff can skip straight to the relevant section.

Proposal 4

The term 'best' needs more clarification. Queried the use of the phrase 'more optimal' in its place. Fertility Plus understand the intent of the proposal but view the 'best' way for people to have children is to have healthy young eggs. All agree that people will probably only use surrogates as a last resort and agree with ACART that where possible, individuals will choose to retain a biological link.

*Case study *a couple had good quality embryos that for an unknown reason were not implanting into the mother. At this time, the 'best' option was to use the help of a surrogate. The embryo implanted and 8 weeks later the intending parents got pregnant naturally, resulting in 2 live births of full genetic siblings, only 8 weeks apart.*

Proposal 5

Part 1: Agree that gametes become a new entity with different considerations once an embryo is created. Either donor egg or donor sperm used to create an embryo; agree consent must be obtained at time of donation but disagree that consent is needed when an embryo is to be used. Consent cannot be withdrawn once embryo is created. Part 2: Embryo donation. As above agree that consent must be obtained at the time of donation but not when recipients are intending to thaw and transfer. The donors retain the right to withdraw their consent up to the time of transfer to the uterus. Donor do not need to be informed of intended thaw and transfer.

Proposal 6

Agree that this is best practice. Clinics will continue operating under the status quo.

Noted that ECART are not the entity in the best position to assess coercion – clinics are.

Concern that this proposal would legally require clinics to apply to ECART, when counsellors feel that some donations are acceptable and free of coercion. Clinics do not want to see wasted resources going to mandatory blanket ethical approval. Instead, the guidelines should say something along the lines of: 'should the clinic professionals have concerns, an ECART application is required.'

Proposal 7

Opinions were divided on this proposal. Unsure if it should be a set policy of 2 families in all cases. Rationale for this is some people have lots of embryos to donate, and will be back to square one where they again need to decide what to do with their surplus embryos.

Some recognised the need to limit to 2 families, as the complexities increase for resulting children. Noted the risk of relationships when they are older also.

*Case study *a Christian couple donated 10 surplus embryos with the condition that all must be given a chance at implantation and none must be destroyed. So far about half have implanted successfully.*

Discussion about the need for further research into the outcomes for children.

Proposal 8

Part 1 – yes agree. Surrogacy situations must have legal advice.

Part 2 – agree that requiring legal advice makes the situation more 'real and serious' – but agree with ACART that it shouldn't be a MUST. Fertility Plus agree with ACART that legal advice isn't always needed, counsellors can and do cover off effectively what would be obtained through legal advice.

Fertility Plus would like to retain the right to recommend people seek legal advice where a specific situation requires it.

Part 3 – Fertility Plus feels as though counselling can cover off 'understanding' where *'all affected parties understand the legal implications of the procedure*'. Perhaps counsellors would satisfy ECART's requirements if they were to put it in the application that 'an applicant had the choice to seek legal advice, but chose not to'. This would protect clinics and could red flag to ECART – who could then defer until legal advice is sought.

Proposal 9

Disagree that all family gamete donations should require ECART approval. The system is robust, works well, and does not need to be regulated. Given this, Fertility Plus holds that no intra generational applications should go to ECART, but inter-generational applications should be continued to be required.

Fertility Plus and Repromed have a policy where they require joint counselling for all family gamete donations. ACART could look at formalising joint counselling as a guideline and requiring it for all other New Zealand clinics too.

Proposal 10

ACART is proposing that the guidelines should enable ECART to approve the donation of embryos created from donated eggs and/or donated sperm, provided ECART takes account of the potential complexity of resulting relationships, and the gamete donors have given consent to the specific use.

Fertility Plus agrees with this proposal but has some reservations. Queried whether this guideline would mean that <u>every</u> situation needs to be covered in counselling? For example, there could be a situation where gametes have reached their 10 family limit, but a family still have frozen embryos using those gametes and refuse to destroy them without giving them a chance at life.

There is the capability to put in an ECART application to extend storage for families not wanting to destroy embryos. Situation; sperm donated and coming up to 10 year limit but embryos created from this sperm are only 3 years old. We would put in an ECART extension application for this as per HART Act to extend the embryo storage past the sperm limit.

Note that if an embryo is to be re donated – a gamete donor's approval must be sought again. This is not a current rule and we would approve and agree with this.

ACART recognises the onus on the counsellors. Fertility Plus noted the best situation may be where embryos are re donated to friends/family in the first instance, because that would be best for the resulting children in terms of ease of access to their genetic identify. Queried whether this could be fed into the guidelines somehow.

Has ACART taken into account that there could be an added level of complexity here if a surrogate is being used in this situation?

Proposal 11

Yes agree that on donation is not acceptable but re donation is. So long as the policy of 2 families with full biological siblings is upheld.

Proposal 12

Part 1 – agree that all embryo donations cases should require ethical approval.

Part 2 – '*embryo donation does not include cases where an embryo created for one couple is used by one of the couple in a new relationship with the informed consent of the previous partner.'*

Disagree. But opinion was split. Majority viewed this situation as embryo donation. View that cases of using embryos with a new partner should always go to ECART due to the complexity and for protection for the clinics.

Regarding part 2: some noted a sexist bias where a man's new partner could gestate an embryo made from his sperm and his previous partner's egg, whereby the new partner would become the legal mother. In this case there is concern for the wellbeing of the man who contributes the sperm. Noted that when this is the case, the application should receive very comprehensive counselling and legal advice.

males would require a 3rd party to carry the embryo whereas the female can just use the embryos herself.

View that for embryo donation cases it is worth getting legal advice in almost all cases.

Fertility Plus reiterated that the wellbeing of any children born from ART is paramount.

Proposal 13

Yes agree. Noted that traditional type surrogacies performed at home are quite prevalent, although we do not have numbers for this.

Clinic assisted surrogacy is the key words here. ECART applications protect all parties.

Other comments

Would the Ministry look at the feasibility of public funding for ECART applications, for people eligible for publicly funded IVF. If they're meeting the criteria for public funding, there is generally a medical reason, and an ECART application costs between $3k-5k.

Noted that it is great that there is a counsellor as a member on ECART.

Page 7 – those present queried the use of MUST where it says 'a surrogate must have completed her family'. It should be changed to 'should'.