

Minutes of the Fortieth Meeting of the Ethics Committee on Assisted Reproductive Technology

29 November 2012

Held on 29 November 2012
Bankside Chambers, 88 Shortland Street, Auckland

In Attendance

Kate Davenport	Chair
Huia Tomlins-Jahnke	
Freddie Graham	
Adriana Gunder	
Brian Fergus	
Deborah Payne	
Kirsten Forrest	Secretariat
Andrew Shelling	Deputy Chair ACART
Chris Wilson	ACART Secretariat

Apologies

Deborah Rowe
Carolyn Mason

1. Welcome

Kate opened the meeting and expressed ECART's sincere condolences to Brian Fergus for his recent loss.

2. Declarations of interest

There were no declarations of interest made regarding applications for review at the meeting.

Adriana Gunder declared that she has been elected to the National Board of the New Zealand Red Cross.

3. Action points from previous meeting

The minutes from ECART's 27 September 2012 meeting were confirmed as an accurate record of the meeting.

4. Application E12/39 for Embryo Donation for Reproductive purposes

Kate opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Embryo Donation for Reproductive Purposes* and the principles of the HART Act 2004.

Issues discussed included:

- The donor couple are foreign nationals who have New Zealand residency but intend to return to their country of origin.
- The donor and recipient couples have considered the impact on any resulting child of the donor couple's intended move and the resulting distance between the families.
- The recipient couple's past experiences have helped them feel that they could take on this arrangement.

- The birth mother's BMI is not currently associated with contraindications to pregnancy.

Decision

- the committee has made their decision, taking into account requirements in guideline 2(a)(i) that *"the recipient or recipient's partner must have a medical condition, affecting his or her reproductive ability, or a medical diagnosis of unexplained fertility, that makes embryo donation appropriate"*.
- the committee was satisfied that RP and RW have a medical diagnosis of unexplained infertility, that makes embryo donation appropriate.
- each party has received appropriate counselling and medical advice.
- the committee was satisfied that there is no coercion apparent within this application and that all parties are entering the agreement fully informed of the potential risks and of their own free will.

The committee agreed to **approve** this application.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision to approve this application.

5. Application E12/40 for Clinic-Assisted Surrogacy

Brian opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy Arrangements involving Providers of Fertility Services* and the principles of the HART Act 2004.

Issues discussed included:

- the intending mother has a long history of trying to conceive and the committee is satisfied that a surrogate is needed.
- the parties have a long-standing relationship.
- the birth mother considers her own family is complete.

Decision

- the committee has made its decision taking into account the guideline in 2(a)(ii) that *"the intending mother has a medical condition that prevents pregnancy or makes pregnancy potentially damaging to her and/or any resulting child"*.
- the committee was satisfied that IM has a medical condition affecting her ability to carry a pregnancy.
- each party has received appropriate counselling, medical and legal advice.
- the committee was satisfied that there is no coercion apparent within this application and that all parties are entering the agreement fully informed of the potential risks and of their own free will.

The committee agreed to **approve** this application.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision to approve this application.

6 . Application E12/41 for Clinic-Assisted Surrogacy

Freddie opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy Arrangements involving Providers of Fertility Services* and the principles of the HART Act 2004.

Issues discussed included:

- there are medical risks to BM given her birthing history. However, the committee was satisfied that the medical risks have been well-explained and understood by the BM and that an appropriate plan is in place to mitigate the risks.
- a medical condition for the intending mother is established and she has known for some time that a surrogate is needed.
- the committee is satisfied that the birth mother's own children know about the intended arrangement.

Decision

- the committee has made its decision taking into account the guideline in 2(a)(ii) that *"the intending mother has a medical condition that prevents pregnancy or makes pregnancy potentially damaging to her and/or any resulting child"*.
- the committee was satisfied that IM has a medical condition affecting her ability to carry a pregnancy.
- each party has received appropriate counselling, medical and legal advice.
- the committee was satisfied that there is no coercion apparent within this application and that all parties are entering the agreement fully informed of the potential risks and of their own free will.

The committee agreed to **approve** this application.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision to approve this application.

7. Application E12/42 for Clinic-Assisted Surrogacy

Kate opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy Arrangements involving Providers of Fertility Services* and the principles of the HART Act 2004.

Issues discussed included:

- appropriate arrangements have been made to support the BM's clear requests for assistance from the intending parents.
- both parties are open and clear about what they need within this arrangement.
- the length of the relationship between the birth parents is uncertain and the living arrangements are unusual but appropriate plans have been set in place should a pregnancy result.
- the implications for a child born of this arrangement.

Decision

- the committee has made its decision taking into account the guideline in 2(a)(ii) that *"the intending mother has a medical condition that prevents pregnancy or makes pregnancy potentially damaging to her and/or any resulting child"*.

- the committee was satisfied that IM has a medical condition affecting her ability to carry a pregnancy.
- each party has received appropriate counselling, medical and legal advice.
- the committee was satisfied that there is no coercion apparent within this application and that all parties are entering the agreement fully informed of the potential risks and of their own free will.

The committee agreed to **approve** this application.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision to approve this application.

8. Application E12/43 for Clinic-Assisted Surrogacy Kate opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy Arrangements involving Providers of Fertility Services* and the principles of the HART Act 2004.

Issues discussed included:

- the ED has a condition that carries a risk of being genetically inherited. The committee was satisfied that the risk was small. The committee was also satisfied that the ED's medical history was disclosed to all parties and accepted.
- the arrangement involved gamete donation
- matters of interest included
 - the age of the BM
 - the way in which the ED met IM and their continued relationship.
- the committee was satisfied that the IM has a medical condition for which a surrogacy arrangement is needed.
- the relationship between the BM and the IM appears sound.
- the parties have discussed how they will maintain a relationship when the intending parents take a planned trip overseas. The committee was satisfied that the interests of any child born of this arrangement have been well-considered.
- the BM has set clear boundaries and the ultimate voice of the BM has been well-considered by the intending parents.

Decision

- the committee has made its decision taking into account the guideline in 2(a)(ii) that *"the intending mother has a medical condition that prevents pregnancy or makes pregnancy potentially damaging to her and/or any resulting child"*.
- the committee was satisfied that IM has a medical condition affecting her ability to carry a pregnancy.
- each party has received appropriate counselling, medical and legal advice.
- the committee was satisfied that there is no coercion apparent within this application and that all parties are entering the agreement fully informed of the potential risks and of their own free will.

The committee agreed to **approve** this application.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision to approve this application.

9. Application E12/44 for Within Family Gamete Donation

Huia opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Donation of Eggs or Sperm between Certain Family members* and the principles of the HART Act 2004.

Issues discussed included:

- ideas about the nature of 'whakapapa' are changing, including from the influence of the available technology.
- an interesting cultural comment is that any child born will be seen as a cousin of GD: in the hierarchical structure of the Maori world, this relationship doesn't make sense.
- the RW will be living in a Maori community and that community will connect the child to GD.
- the recipient couple and their immediate family will see a child as their natural child.
- a whole of whanau approach is seen with the collective support for GD in making this decision, and this has been well-addressed in the counselling reports. No evidence of coercion is apparent.
- GD's medical condition is well-managed and the committee was satisfied that there would not be any risk to a child born of this arrangement.
- the medical report for GD sets out the risks very well.

Decision

- the committee has made their decision taking into account the requirements in guideline 2(a)(i) that *"the recipient or recipient's partner must have a medical condition affecting his or her reproductive ability, or a medical diagnosis of unexplained fertility, that makes egg or sperm donation appropriate"*
- the committee was satisfied that RP has a medical condition affecting her reproductive ability
- each party has received appropriate counselling and medical advice.

The committee agreed to **approve** this application.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision to approve this application.

10. Application E12/45 for Within Family Gamete Donation

Adriana opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Donation of Eggs or Sperm between Certain Family members* and the principles of the HART Act 2004.

Issues discussed included:

- the donating couple's medical history has been disclosed and the recipient couple is happy to proceed with the arrangement despite the small risk of a congenital abnormality.
- the number of embryos to be transplanted to RW will depend on the quality
- the relationship between the parties appears sound and no evidence of coercion is apparent.

Decision

- the committee has made their decision taking into account the requirements in guideline 2(a)(i) that *"the recipient or recipient's partner must have a medical condition affecting his or her reproductive ability, or a medical diagnosis of unexplained fertility, that makes egg or sperm donation appropriate"*
- the committee was satisfied that RW has a medical condition affecting her reproductive ability
- each party has received appropriate counselling and medical advice.

The committee agreed to **approve** this application.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision to approve this application.

11. Application E12/46 for Within Family Gamete Donation

Kate opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Donation of Eggs or Sperm between Certain Family members* and the principles of the HART Act 2004.

Issues discussed included:

- the RW was pregnant when the application was submitted to ECART.
- the GD in this arrangement will be the second member of the family to donate.
- the RW is still pregnant but the pregnancy is considered vulnerable.

Decision

- the committee has made their decision taking into account the requirements in guideline 2(a)(i) that *"the recipient or recipient's partner must have a medical condition affecting his or her reproductive ability, or a medical diagnosis of unexplained fertility, that makes egg or sperm donation appropriate"*.
- the committee was satisfied that RW has a medical condition affecting her reproductive ability.
- each party has received appropriate counselling and medical advice.

The committee agreed to **defer** this application and ask the clinic to update ECART about whether or not RW's pregnancy continues.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision to defer the application.

12. Application E12/47: Application for Embryo Donation for Reproductive Purposes

Huia opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Embryo Donation for Reproductive Purposes* and the principles of the HART Act 2004.

Issues discussed included:

- the intended transfer of two embryos at the time of their creation. The risk to the birth mother of a multiple pregnancy could be avoided.
- the recipient couple is aware of the donor woman's medical condition and its history. The committee questioned whether the condition would have any impact on a child born of this arrangement and agreed that the genetic risk was low.
- while a child born of this arrangement would not be a full genetic child of the recipient couple, he or she would be recognised by the courts as the child of the recipients, with the entitlements that come with that status.
- the recipient couple's past experiences have helped them feel able to raise children who are not genetically their own.
- both parties share the same clinician but all discussions in respect of the donations were independent of each other.
- the friendship is long-standing and the parties appear to agree about the terms of the donation.
- the impact on the donor woman needed to be considered, because a child born of the donation would be a full genetic sibling to her own young child.
- the donor woman has clearly stated that she considers her family is complete and that she prefers another couple to have a chance to have a family. The committee considered that the donor couple has had enough time to consider the donation.

Decision

- the committee has made their decision taking into account the requirements in guideline 2(a)(i) that *"the recipient or recipient's partner must have a medical condition, affecting his or her reproductive ability, or a medical diagnosis of unexplained fertility, that makes embryo donation appropriate"*
- the committee was satisfied that RW has a medical diagnosis of unexplained infertility that makes embryo donation appropriate
- each party has received appropriate counselling and medical advice
- the committee was satisfied that there is no coercion apparent within this application and that all parties are entering the agreement fully informed of the potential risks and of their own free will.

The committee agreed to **approve** this application with the recommendation that a single embryo transfer is carried out.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision.

13. Application E12/48 for Clinic-Assisted Surrogacy

Debbie opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy Arrangements involving Providers of Fertility Services* and the principles of the HART Act 2004.

Issues discussed included:

- the application does not include a letter from Child Youth and Family (CYF)
- a medical condition is clearly established for the IM
- the BM is at increased risk of developing gestational diabetes and therefore her health is a factor to be considered
- the risk to the BM is minimised with a single embryo transfer.
- neither party has told their parents of IM's history or their decision about the surrogacy arrangement. There will be disclosure, however, if a pregnancy is achieved.
- a strong and long-standing relationship exists between the parties, and they have been aware of the need for a surrogacy arrangement for some time.
- a child born of this arrangement will be genetically related to the parties because the birth mother is a blood relation of one of the intending parents.
- the joint counselling report addresses the issues well and shows that the parties agree on issues around potential termination and the rights of the birth mother because she is carrying the pregnancy.

Decision

- the committee has made its decision taking into account the guideline in 2(a)(ii) that *"the intending mother has a medical condition that prevents pregnancy or makes pregnancy potentially damaging to her and/or any resulting child"*.
- the committee was satisfied that IM has a medical condition affecting her ability to carry a pregnancy.
- each party has received appropriate counselling, medical and legal advice.
- the committee was satisfied that there is no coercion apparent within this application and that all parties are entering the agreement fully informed of the potential risks and of their own free will.

The committee agreed to **approve** this application upon receipt of confirmation that the parties have applied for CYF approval.

Actions

Secretariat to draft a letter from the Chair to the clinic informing the medical director of the committee's decision to approve this application pending receipt of confirmation that the parties have applied for CYFS approval.

14. Correspondence

The committee **noted** the correspondence to and from ECART since the meeting of 27 September 2012:

- a query from a member of the public about the timeframe and process for using an embryo created for reproductive purposes from an egg donor and a sperm donor. In response, ECART outlined that the process could take three to six months depending on whether the egg donor was known to the recipient and whether individual clinics would allow for a three-month stand down if this was the case.
- a letter from a Fertility Associates counsellor requesting advice from ECART about how to proceed with an application for extension of approval. Following discussion, a consensus was reached that the committee would like to see confirmation that all parties agree to the extension request and that there has been no significant change in circumstances. The committee would also like to see a medical review for the parties. The secretariat will advise the counsellor of the above in writing.
- a letter from the Fertility Associates counsellors, which requested that question 6.11 in the joint counselling report for within-family gamete donations be moved to section 5: Report by counsellor for the recipients. This prompted discussion around the disclosure of information that may be relevant and important for both parties to know. The committee was concerned that removing the question from the joint counselling session could result in some important information not being discussed between both parties and may work against the concept of 'openness'. Following discussion, a consensus was reached that the committee would like the counsellors to confirm how they will make the distinction between details that are personal to individuals but not relevant to both parties. Secretariat will write asking how the counsellors propose to distinguish between what is relevant and what is irrelevant.
- a query from a researcher asking whether ECART had received any requests for pre implantation genetic diagnosis for identifying embryos who may either be born deaf or develop deafness as a consequence of gene mutation. The ECART secretariat responded that there are no records of such requests having been made.
- a query from a member of the public asking about the process for surrogacy. The ECART secretariat responded advising that the committee meets five times each year to review applications made through fertility clinics. The secretariat advised that the best thing to do in the first instance would be to contact the nearest fertility clinic and arrange to find out more information about the process with the clinic.
- correspondence received from ACART which attached some ACART documents for ECART's information: ethical framework, list of established procedures, a paper on pre-implantation embryology, a report of conference attendance. The first three documents will be routinely given to new ACART members. The committee appreciated the correspondence and the secretariat will write to ACART to express thanks for ACART's openness. The ECART secretariat will also post the ACART framework on its website.

- The committee **noted** the decision letters from the ECART 27 September meeting.

15. ACART minutes

The unconfirmed minutes from the fortieth ACART meeting held on 28 September 2012 were **noted**

16. General business

The committee discussed the first draft form for applications for extending the storage period of gametes and embryos. The secretariat will make the following changes to the form before sending the form to the clinics and ACART for feedback.

- more provision for parties to give reasons for requesting an extension.
- set out section 3a of the guidelines about 'reasonable efforts' and the HART Act principles to state that ECART will make a decision on the basis of the reasons given.
- remove sperm donor from the embryo donation application form and ask for the consent of the donor couple.
- create a new form for sperm donors as clinics are likely to make applications on behalf of sperm donors.

The committee discussed what ECART would consider to be 'reasonable effort' by clinics and or individuals to gain consent from all parties for the extension application. It was noted that it is difficult for ECART to anticipate everything that constitutes reasonable effort at this point in time and that to some extent ECART would be learning as it goes.

Concern was expressed that the application forms would disclose information not previously seen by ECART. If clinics make an application identifying details could continue to be omitted and ECART will ask for suggestions from the clinics about how they could continue to ensure that parties involved in applications remain anonymous. ECART will send the amended forms out to the clinics as soon as possible.

17. Conclusion of meeting

The committee confirmed the next ECART meeting date of 7 March 2013 to be held at Deloitte House, Wellington.

Actions

Secretariat to write to the counsellors at fertility clinics in response to the letter of 5 October 2012, and seek clarification on how the counsellors will distinguish between relevant and irrelevant personal information for disclosure to both parties in embryo donation applications.

Secretariat to write to the counsellor at Fertility Plus in response to the letter of 1 November 2012 and advise that the committee would like to see: evidence that all parties agree to the extension of approval request, that there have been no significant other changes in the situation and a medical review.

Secretariat to write to ACART and thank them for the correspondence dated 5 October 2012.

Secretariat to post ACART's ethical framework on ECART's website.

Secretariat to make agreed changes to the draft extension application forms and send the forms to clinics and ACART for feedback as soon as possible.

The meeting closed at 1.30pm.