

Minutes of the Sixty-first Meeting of the Ethics Committee on Assisted Reproductive Technology

8 September 2016 and 15 September 2016

Held on 8 September 2016
at Novotel Ellerslie, Auckland and,
Held on 15 September 2016
by videoconference

In Attendance

Iris Reuvecamp	Chair
Carolyn Mason	Member
Deborah Payne	Member
Freddie Graham	Member
Judith Charlton	Member
Paul Copland	Member
Jo Fitzpatrick	Member
Kirsten Forrest	ECART Secretariat
Alison Douglass	ACART Member in attendance

1. Welcome

Iris Reuvecamp opened the meeting.

2. Confirmation of minutes from previous meeting

The minutes from ECART's 7 July 2016 meeting were confirmed subject to the following amendments:

Page 5, correct reference to Jo Fitzpatrick, not Fitzgerald.

Page 9, note the decision to 'approve' application E16/46

3. Application E16/62 for Research on non-viable embryos

Dr Paul Copland opened the discussion for this application. The committee considered this information in relation to the *Guidelines for Research on Gametes and Non-Viable Embryos*.

Issues discussed included:

- This study will look at day five embryos that are determined to be aneuploid by pre-implantation genetic screening and therefore considered to be clinically non-viable.
- Embryos that are clinically non-viable due to aneuploidy but potentially compatible with life such as trisomy 21, 13 15, 46XO or 47XXY are excluded from the research.
- The committee queried what the background is to pre-implantation genetic screening and whether it is currently used in New Zealand. The researcher confirmed that Canterbury Health Laboratories has recently introduced clinical testing in NZ and that the method has been used and applied for 10 years overseas.
- The researchers wish to quantify the mitochondrial DNA copy number to see whether it is a useful measure of selecting the best embryo to transfer during an IVF cycle. The researchers will disaggregate the embryo and assay the trophoblast and ICM cells for numbers of mitochondria to assess intra-embryo variability in mitochondria numbers.
- The committee discussed what proportion of embryos were expected to be aneuploid and at what stage in embryo development the aneuploidy occurred. Dr Morbeck confirmed that it is age dependent and looking at eggs alone aneuploidy starts at 20 percent in young women and increases to 60 percent in women aged 40. Approximately 2/3rds of the observed aneuploidy is thought to occur at the meiotic division during oogenesis.
- In relation to confidentiality of patient health information the committee noted that there is no mention of what information will be passed on from the clinician, and what patient data is required to go with the tissue.
- The research team have stated in the application form that the fertility rate is decreasing at a higher rate for Māori than non- Māori in the last 40 years. While at this meeting the committee were advised that Māori participants are likely to be few or none in this study, given the above statement in the application form, the potential for Māori participants, the fact that tissue will be collected and used and, the importance of health research as an enabler of improving health outcomes for Māori generally, the committee recommended that the researchers consult the Te Ara Tika Guidelines and also a Māori Research cultural advisor or group to ensure that any potential issues for Māori are addressed.

The committee requested the following changes to the participant information sheet and consent forms:

- The committee asked that more detail be provided on page 2 of the information sheet (third paragraph), specifically the nature of the embryos being used. The committee suggested that the term “not compatible with life” may be a description that is acceptable for a lay audience. Other suggested wording included “would not result in a live birth” or “would not transfer successfully”.

- The participant information sheet should be amended to detail exactly what health information about the donor(s) the researchers wish to collect.
- The consent form should be amended to indicate consent to the collection of the specified health information.
- The consent form should be amended to include signatures for both the gamete donors of the embryos in question.
- In relation to the disposal of tissue, the committee noted that Part 6, Risks and Benefits, number 43 stated that the only potential risk is that at a later date the participants may regret donating their embryo for research and that in order to minimise this risk, participants will be given information about the project and will be advised that once the clinic collects the embryo it cannot be returned to them. It was suggested that a sentence be included that embryos will not be returned to participants on page 3 of the information sheet under the heading 'What are the risks and benefits of taking part?'
- Collection and use of tissue: the body is considered Tapu by Māori and Indigenous people generally. The committee noted that there is no indication about whether cultural considerations such as discarding of tissue in a culturally appropriate way will be taken into account. The committee recommended the following statement: *You may hold beliefs about a sacred and shared value of all or any reproductive tissue samples. The cultural issues associated with storing and discarding your tissue should be discussed with your family/whanau as appropriate. There are a range of views held by Māori around these issues; some iwi disagree with storage of samples citing whakapapa and advise their people to consult prior to participation in research where this occurs. However, it is acknowledged that individuals have the right to choose.*"

Decision

The committee agreed to **defer** this application and agreed that it will consider a response to the further information requested above in between scheduled meetings.

Actions

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

5. Application E16/63 for Research on Gametes

Dr Paul Copland opened the discussion for this application. The committee considered this information in relation to the *Guidelines for Research on Gametes and Non-Viable Embryos*.

Issues discussed included:

- This study aims to look at developing a sensitive, cost effective and practical test for embryo-toxicity of mineral oil used for in vitro culture of human embryos. The researchers will use a human sperm motility assay to assess its sensitivity for use in detecting contaminants in mineral oil. A mouse

embryo assay is currently used but it is described as being expensive and impractical.

- The committee noted that participants will be asked to donate sperm for this study and that an incidental finding may be that of infertility. The committee suggested that in this case the researchers offer the participants the chance to opt out of being told the results rather than opt in.
- The committee alerted the researchers to the need to take extra care that all information from this study is kept confidential given the nature of the group of participants, and especially if there are incidental findings. The committee suggested, for example, that it is made clear to participants who will have access to information about them. If participants know exactly what will be done then they can have a level of comfort about their confidentiality being respected and be fully informed.
- The research team have stated in the application form that the fertility rate is decreasing at a higher rate for Māori than non- Māori in the last 40 years. While at this meeting the committee were advised that Māori participants are likely to be few or none in this study, given the above statement in the application form, the potential for Māori participants, the fact that tissue will be collected and used and, the importance of health research as an enabler of improving health outcomes for Māori generally, the committee recommended that the researchers consult the Te Ara Tika Guidelines and also a Māori Research cultural advisor or group to ensure that any potential issues for Māori are addressed.

The committee requested the following changes to the participant information sheet and consent forms:

- The committee noted the absence of a consent form in the papers before it. The researcher agreed to follow up on this and provide a consent form for the committee. Following the meeting the researcher contacted the ECART Secretariat to advise that a consent form was originally submitted with the application. The secretariat can provide a copy to the committee.
- The committee noted that the information sheet is light on detail about what the study will involve and asked that the researchers revisit the wording and set this out in more detail including information about where the study will take place and how long it will take.
- The Committee suggested specifying that samples would be discarded after use and noting the cultural considerations around this use and disposal of tissue for Maori.

Decision

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

Actions

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

6. Application E16/64 for Embryos created from donated eggs and donated sperm

Ms Jo Fitzpatrick opened the discussion for this application. The committee considered this information in relation to the *Guidelines on the Creation and Use, for Reproductive Purposes, of an Embryo created with Donated Eggs in conjunction with Donated Sperm* and the principles of the HART Act 2004.

Issues discussed included:

- The recipient couple in this application are a couple who have had an extensive reproductive journey with treatment that has spanned some years. Medical opinion is that they are at the point where the use of donor eggs is would give them the best chance of success and as they are a same sex couple, there is a need for donor sperm. This application covers both RW and RP potentially having treatment with the embryos created, but at different times.
- Both the sperm donor and the egg donor are known to the couple through familial and friendship connections. Having donors with known connections is important to the recipient couple. It appears that due to the relationships held with the donors that there will be ongoing contact with any child born and this aspect has been well thought through.
- The egg donor in this application has not had children and has not ruled out having them herself. The committee noted the implications of this donation for the egg donor including risks to her future fertility and relationships, her motives for offering to donate, and openness to future contact with any child born were well canvassed in the counselling report. She showed a keen awareness of meeting the needs of any resulting child. She has thought through consent issues.
- The counselling sessions for the sperm donor have also comprehensively covered the implications for him, including discussion around donating conditions, future contact with any child born and the potential impact on his own children of having biological half brothers or sisters.
- The committee noted that all parties in this application understand that embryos created in this treatment can only be used by the recipient couple and not donated to another family.
- In terms of protecting the future child: everyone is open to future contact and the relationships between the parties safeguard the welfare of all including the child. The child will have access to his or her whakapapa. The parties were happy that the counselling was culturally appropriate. It was offered for extended family and friends. Some extended family and friends have met and formed a relationship.
- The counselling for the recipient couple was thorough.
- The committee noted that the inconsistent way in which the recipient couple were referenced in this application caused confusion about who would have treatment and when. The medical information in section 1.15 of the application referred to the couple as BM#1 and BM#2, and the medical report for the recipients referred to them as RW(a) and RW(b). The counselling reports used RW and RP, which is consistent with the identifiers used for recipient couples for this type of application. It took some time for the committee to establish the order of who will have treatment and when given the differing identifiers stated. The committee noted that it would be helpful if consistent identifiers could be used in the interests of clarity.
- The committee noted that the medical report for the recipient couple did not give a medical assessment for 'RW(a)' It agreed to approve this application for

'RW(b)' and requests a supplementary medical report be provided for RW(a) that assesses the medical implications for her.

Decision

The committee agreed to **approve** this application for RW(b). The committee agreed to **defer** this application for RW(a) pending receipt of a medical report that assesses the medical implications for her.

Discussion held on 15 September 2016

- A medical report for RW(a) was submitted prior to this meeting. ECART was satisfied that it did not raise any issues.

Decision

The committee agreed to **approve** this application for RW(b) and RW(a).

Actions

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

7. Application E16/65 for Surrogacy involving an Assisted Reproductive Procedure

Dr Carolyn Mason opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy involving an Assisted Reproductive Procedure* and the principles of the HART Act 2004.

Issues discussed included:

- The committee noted the medical reason for surrogacy being needed adding that the risk of future complications for the intending mother is low but not insignificant. Given the intending mother's previous experience ECART is sympathetic to the need for a surrogate rather than risking the intending mother's health.
- In further discussion on the genuine medical reason for surrogacy, ECART noted that it must be satisfied that proposed surrogacy is the best or only opportunity for at least one of the intending parents to be a genetic parent including for the examples of reasons given in the guidelines. ECART agreed that on the basis of the information before it that the application does fall within the ambit of the examples stated. ECART agreed that there would be a risk to the child and a risk to the intending mother in this application if she carried a pregnancy herself.
- The intending parents are likely to produce viable embryos and any child born will have a genetic link to them.
- The relationships between the parties in this application. There is a within family aspect to this application in that the birth mother is the intending mother's sister.
- The committee discussed the timing of the birth mother carrying a pregnancy for her sister in light of the ages of her own children. This appears to have been thought through and canvassed in counselling sessions. The birth mother

appears to have practical and emotional support in place and this mitigated the committee's concern. The birth mother's eldest child has been included in the counselling process.

- Testamentary guardianship has been discussed and agreed. The birth parents have agreed to act as testamentary guardians and the committee noted that this agreement made sense in the context of this family's existing arrangements where the birth parents are guardians for the intending parents' existing child.
- The applicants understand the concept of 'openness'. There are plans in place to document events to help the future child understand their conception journey.
- There appeared to be some differing information stated about the possibility of termination of pregnancy if it is found that a child may be born with a disability but the committee agreed that this was not to the extent that it would cause problems as the intending parents have stated that they would accept a child with some degree of disability. The parties have indicated that they would discuss in an open way if the need should arise.
- The committee noted that a letter from CYFS stating approval of an adoption order in principle was not submitted with the application and agreed to approve the application subject to receipt of this letter.

Decision

The committee agreed to **approve** this application subject to receipt of a letter from CYFS that notes approval in principle of an adoption order.

Actions

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

8. Application E16/66 for Surrogacy involving an Assisted Reproductive Procedure

Dr Deb Payne opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy involving an Assisted Reproductive Procedure* and the principles of the HART Act 2004.

Issues discussed included:

- The intending mother's obstetric history and the reasons that surrogacy is the best option for the intending parents. The intending mother's medical report detailed how she was negatively affected by previous treatment. The history is extensive and the intending mother's uterine environment has been impaired and she has a reduced ability to conceive.
- The birth mother's birthing history. She is multiparous and obstetric care is recommended for any further pregnancy she might carry. Medical opinion is that her birthing history does not threaten her well-being in any further pregnancy that she might carry.
- The committee noted that the counselling reports show that the intending parents have invested considerable time and energy into having another child.
- The way in which the birth parents and the intending parents met (via social media), and how long they have known each other for. There is no evidence

of coercion or financial incentive for the birth parents. The counselling reports show that both parties have indicated there will be openness with any child born of this arrangement and also a commitment to continuing their relationship. The birth mother has raised her decision with her children.

- The counselling sessions have canvassed the pregnancy and birthing plans for the birth mother and there is an agreed plan in place. There is agreed support in place for the birth mother during any pregnancy she may carry.
- Emotional issues for the intending mother in light of her journey to date and ways in which to manage this have been discussed. The birth mother feels that she is able to set boundaries and has identified an independent person to approach if needed.
- ECART noted that there is complexity to this case given the intending parents' loss and their significant investment placed in their journey to date.
- The issue of termination of pregnancy and the applicants' views: the committee noted that the intending parents had, in their individual counselling session, stated that a decision to terminate a pregnancy would be very difficult for the birth mother. Their own wish would be for a termination if an abnormality of considerable severity was diagnosed but that they would be willing to accept whatever the birth mother thinks is appropriate for her. Both the individual counselling report for the birth mother and the joint counselling report are silent on discussion of this issue and it is not clear to the committee what the birth mother's views are or whether there has been shared discussion and agreement on this difficult topic. The committee would like to be reassured that there has been discussion and agreement in this regard as if the birth mother chooses not to terminate a pregnancy this will impact on the intending parents as they intend to adopt any child born and will care for the child. The committee wants clearer information about whether the intending parents would be prepared to accept a child born with a disability in order to be reassured that both parties are clear about who will take responsibility for a child.
- The birth mother has stated in her individual counselling session that the intending parents will cover her life insurance throughout any pregnancy and for three months after a birth. The intending parents' individual counselling report stated that the issue of life insurance had not been discussed between the two parties and that it would be discussed at the joint counselling session. The joint counselling session did not document any shared discussion and agreement in this regard.
- The committee noted that the counselling report stated that the birth mother told the counsellor that she and BP have told their children in simple language the intended plan to carry a baby for IM and IP but that the report went on to say that counselling for the children would not be needed now but may be in the future. The committee agreed that it appeared that they were thinking about the potential of their children having counselling in the future. They are approaching it in an appropriate way for now and not closing the door on the possibility of future counselling.

Decision

The committee agreed to **defer** this application to seek clarification that there has been discussion and agreement as stated in the birth parents' individual counselling report, that the intending parents will pay for insurance for the birth mother while she is

pregnant and for three months following a birth and the intending parents' view. ECART also requests clearer information about the birth mother's views on the difficult topic of termination of pregnancy and also whether the intending parents would be prepared to accept a child born with a disability in order to be reassured that both parties are clear about who will take responsibility for a child.

Actions

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

ECART to write to ACART requesting advice regarding the application of sections 14 and 15 of the HART Act to the commonplace use of Facebook to find a surrogate.

9. Application E16/67 for Surrogacy involving an Assisted Reproductive Procedure

Ms Iris Reuvecamp opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy involving an Assisted Reproductive Procedure*, and the principles of the HART Act 2004.

Issues discussed included:

- Any child born will be a full biological child of the intending parents. The intending parents are both Maori. They have one child together.
- The intending mother's pregnancy history and illness justifies the need for a surrogate. The key issue in this application is that the intending mother is suffering from a terminal illness and her prognosis is unclear in terms of time. She is however, well currently and what came out throughout this application is the optimistic and positive way she is living her life with her partner and their wider whanau.
- The intending parents have both signed consent forms saying that the intending mother consents to their embryos being used in the event that the intending mother dies.
- The birth mother is related to the intending mother and their relationship is described as close. The intending parents have received offers from other family members. However, they felt that the birth mother in this application is most appropriate as she has completed her family.
- The birth mother has had some health issues but they have been monitored and managed by both herself and with the support of her family. There are no medical concerns about her carrying a further pregnancy.
- The intended arrangement is well-supported by the applicants' respective whanau and letters from both sets of parents supporting this application are included.

- The birth parents appear open and willing to discuss the intended arrangement with their own children and have already started a discussion with them.
- Key issue is the interests of the child given that the IM may not have very long to live.
- With respect to the CYFS report, the intending parents' lawyer argued that it is not for the social worker to determine whether they are fit as ultimately this is a decision for the judge to make. \The intending parents' lawyer feels confident that they could convince a judge that adoption by the intending parents is appropriate.
- The committee noted that this is a very considered and supported application. There has been extensive consideration about how any child born will be cared for. The child would be supported by an extended whanau who are committed to the child's wellbeing.

Decision

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

Actions

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

10. Application E16/68 for Surrogacy involving an Assisted Reproductive Procedure

Mrs Jude Charlton opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy involving an Assisted Reproductive Procedure* and the principles of the HART Act 2004.

Issues discussed included:

- The committee was satisfied that the intending parents have a clear medical reason that makes surrogacy appropriate. The intending parents have considered the idea of surrogacy over time and have had implications counselling.
- It is clear that no money will be exchanged between the parties and that the intending parents will only cover pregnancy-associated costs.
- The relationship between the parties in this application appears to protect the safety and well-being of all including that of any child born.
- The length of time that the couples have known each other is mitigated by fact that they are living in the same town and intend to develop their relationship further.
- The committee noted that some of the important issues flagged in individual counselling sessions for discussion in the joint counselling were not pulled together there. For example, the issue of shared discussion and views on the issue of termination of pregnancy. The counselling report for the intending parents stated the circumstances in which they would accept a legal termination but that they acknowledged that the decision ultimately rests with the birth mother. No information about the birth mother's views on this issue was stated in her individual counselling session nor in the joint counselling session.

- The committee would like confirmation that discussion on the difficult issue of termination of pregnancy has taken place with the birth mother in her individual counselling session and also in the joint counselling session and also requests further information about what the couples have agreed about the use or disposal of any surplus embryos.
- The way in which they are going to have ongoing contact during and after a pregnancy is also missing in part. The counselling report for the birth parents refer to this, but the joint counselling report is silent on whether this was discussed by both parties. The committee noted that the birth mother is planning birth by caesarean section and that she only wants her husband in the birthing suite. The committee would like confirmation that the intending parents know this.
- The question of life insurance for the birth mother was flagged to be raised at the joint counselling session but the report does not follow through on this. The committee requests confirmation that this was discussed and agreed.

Decision

The committee agreed to **defer** this application to request confirmation that the issues of life insurance for the birth mother, termination of pregnancy, pregnancy and birthing plan and the use or disposal of any surplus embryos have been discussed between the parties, and to be provided with details of what was agreed.

Actions

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

11. Application E16/69 for Embryo Donation

Dr Freddie Graham 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 in this application have completed their family. They would like to donate their remaining embryos to the recipient couple who have a need for embryo donation as they have a genetic condition that would likely be passed on to their own children if they were to use their own embryos. The counselling report for the recipient couple states that they have had pre-implantation genetic diagnosis following IVF treatment and that none of the embryos created were unaffected.
- Family inheritance has been discussed in the counselling sessions and in the donor individual counselling session the donor couple's understanding of the recipient couple's need for embryo donation is set out. The donor couple understand that the recipient woman is a carrier and that the recipient man is a fully affected person who currently has no symptoms. The donor couple believe that this will not get in the way of active parenting over the majority of a child's life as the recipient woman will not have symptoms and the recipient man will have gradual onset. The committee's

understanding of the genetic condition is that both the recipients would be affected and develop symptoms and queried whether the donors had information that would allow them to make a fully informed decision about this donation. The committee agreed that would like to see further information from a genetic counsellor that has a prognosis for the recipient couple, confirmation that the donor couple know about the prognosis and have had a discussion about this.

- There was no indication in the application of the support that would be in place for the recipient couple when they become symptomatic. The committee discussed the well-being of a child who could end up providing care for the recipient couple. The committee would like to know what mechanisms or plans are in place to support the recipient couple and any child born of this donation.

Decision

The committee agreed to **defer** this application to request a prognosis from a genetic counsellor for the recipient couple, that the genetic counsellor conveys the prognosis to the donor couple. The committee would like to know that the applicants have discussed the implications of the recipient couple's condition and the support networks that are in place to support the recipient couple.

Actions

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

12. Application E16/70 for Surrogacy involving an Assisted Reproductive Procedure

Dr Freddie Graham opened the discussion for this application. The committee considered this information in relation to the *Guidelines on Surrogacy involving an Assisted Reproductive Procedure* and the principles of the HART Act 2004.

Issues discussed included:

- The intending mother's medical history and fertility history, the effects of which decrease the odds of her successfully carrying a pregnancy. The committee was satisfied that there is a legitimate reason for the intending mother needing a surrogate. The intending parents have had embryos created through IVF treatment.
- The committee discussed whether in the interest of the health and well-being of any child born, the likelihood of a condition being passed on. It was noted that the condition was more likely to be environmental in origin rather than genetic.
- The important considerations for the birth mother in carrying a pregnancy given her birthing history. Although a certain aspect of her birthing history is unusual, the risks to her carrying a further pregnancy are considered to be low.
- The birth parents have completed their own family.
- The counselling sessions have covered the birth mother's motivation for acting as a surrogate and the committee has no concerns in this regard. The birth mother is presented as having thoroughly considered the issues associated with acting as a surrogate and it appears that she is fully informed.

- The committee complemented the counsellors on an application that showed extensive counselling and covered the issues well.

Decision

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

Actions

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

13. Application E16/71 for Surrogacy involving an Assisted Reproductive Procedure

Ms Iris Reuvecamp opened the discussion for this application. The committee considered this information in relation to the *Guidelines for Surrogacy involving an Assisted Reproductive Procedure* and the principles of the HART Act 2004.

Issues discussed included:

- There is an interfamily aspect to this relationship.
- The intending parents live in New Zealand and the birth parents live offshore and it is not clear whether they have New Zealand nationality (they state nationality of the country they reside in). This raises several issues for the committee: the issue of jurisdiction in the event of a dispute between New Zealand and the birth parents' country, whether there are any immigration issues for the birth parents who are intending to come and live in New Zealand for the third trimester of the pregnancy and the third that of access to medical care in New Zealand.
- The birth parents are intending to come to New Zealand for the third trimester of the pregnancy with the expectation that the baby is born in New Zealand. The committee noted that there is a risk that the baby is born offshore rather than here as currently intended. Associated medical costs could be substantial for non-residents/citizens.
- The committee queried whether there might be any laws that prevent the birth parents coming to New Zealand for an extended period of time and also whether there might be any issues with the ability for the intending parents to adopt any child born.

Decision

The committee agreed to **defer** this application to request further information about the issues stated above.

Actions

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

ECART to request general advice from the Ministry of Health Legal team about the laws that apply when a surrogate who is not a New Zealand resident or citizen gives birth in New Zealand along with a request for general advice on eligibility for non-residents or citizens to access to health services in New Zealand. The committee asks whether Australia and the Pacific Islands have differences in relation to New Zealand.

14. Application E16/72 for Surrogacy involving an Assisted Reproductive Procedure

Ms Jo Fitzpatrick opened the discussion for this application. The committee considered this information in relation to the *Guidelines for Surrogacy involving an Assisted Reproductive Procedure* and the principles of the HART Act 2004.

Issues discussed included:

- If ECART approves this application this will be the second surrogacy arrangement for the intending parents. They have one child together who was born with the help of a different surrogate mother who was a family member.
- The way in which the couples met and the length of time they have known each other. They have developed a strong bond and friendship that they think will remain even if the intended arrangement is not successful. The counselling reports have canvassed the issues around pregnancy and birthing plans, adoption and testamentary guardianship of the child and ongoing contact. The relationship between the couples appears to safeguard the health and well-being of all parties including any child born.
- The birth parents have completed their family.
- The legal reports submitted are extensive, and have covered the legal issues well including the status of the intending parents and birth parents at treatment, birth and adoption. The intending parents' legal report has covered life insurance and birth procedures. Inheritance, support and cultural issues have also been covered in the birth parents' legal report.
- The birth mother's motivation for acting as a surrogate - she has researched surrogacy extensively and has an understanding of the process.
- The birth mother's medical and birthing history has been well described and there are well thought out plans and strategies in place to ensure her well-being and that of any child she may carry.
- The committee noted that the birth parents' children were not involved in the counselling sessions as they could not come together. ECART would like to make it clear that the children can have counselling independent of each other and do not have to attend at the same time.
- The counselling report for the intending parents states that they are aware that "it is illegal" to pay anything other than legal and medical costs for the birth mother. The committee commented that there are other pregnancy associated costs that they can cover without acting illegally.

Decision

The committee agreed to **approve** this application noting that the birth mother may wish to consider seeking advice from a specialist due to her recent surgery. The committee would like to make clear that the birth parents' children have the option of attending counselling sessions independent of each other. In terms of pregnancy related costs, the committee noted that the application stated that the intending parents are aware that it is illegal for them to pay anything other than legal and medical costs for the birth parents. The committee notes that there are other pregnancy-related costs that they can cover without acting illegally.

Actions

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

15. Application E16/73 for Within Family Gamete Donation

Iris Reuvecamp opened the discussion for this application. The committee considered this information in relation to the *Guidelines for the donation of gametes between certain family members* and the principles of the HART Act 2004.

Issues discussed included:

- The age of the egg donor. The committee noted its initial concern in this regard but based on the information presented in the application it was satisfied that there is no suggestion that there is concern about her not doing this in a considered way. The committee discussed the donor's living situation and was reassured that the other parties in this application are committed to keeping her best interests at heart.
- The donor couple don't appear to have completed their family but are informed of the risks and wish to proceed.
- There is a clear medical reason for the recipient woman not being able to use her own eggs to conceive.
- There appears to be a close relationship between the couples that safeguards their well-being and also the well-being of any child born. They intend to be open and have told close family members who their donor is.
- The couples have indicated that they are comfortable that the counselling has been culturally appropriate.

Decision

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

Actions

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

16. Request to extend approval for application E13/35 for Embryo Donation

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 recipients have had a child and would like to continue with further treatment for another child. The embryo donors have been contacted and have given their consent. The recipients and donors have kept in touch with

each other through the clinic counsellors. A request to extend storage was previously approved by ECART to 2021.

Decision

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

Actions

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

17. Application E16/52 to Extend Storage of donor sperm and embryos

The committee considered this information in relation to the *Guidelines for Extending the Storage Period of Gametes* and the principles of the HART Act 2004.

Issues discussed included:

- The donor sperm used to create the embryos is set to expire although the embryos were more recently created.
- The donor has consented to a further five years' extended storage.
- The applicants have a child and would like to have another full sibling/s for their child.

Decision

The committee agreed to **approve** this application for five years.

Actions

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

18. Application E16/53 to Extend storage of embryos created with donor sperm

The committee considered this information in relation to the *Guidelines for Extending the Storage Period of Gametes* and the principles of the HART Act 2004.

Issues discussed included:

- The donor sperm used to create the embryos is set to expire although the embryos were more recently created.
- The donor has consented to a further five years' extended storage.
- The applicants have children and would like to have another full sibling/s for their children.
- The committee discussed approving storage for 10 years even though the donors have requested five years. The committee agreed to approve an extension in line with the donor consent.

Actions

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

Decision

The committee agreed to **approve** this application for five years.

19. Application E16/55 to Extend Storage of embryos created with donor sperm

The committee considered this information in relation to the *Guidelines for Extending the Storage Period of Gametes* and the principles of the HART Act 2004.

Issues discussed included:

- The applicant is seeking an extension of one year and intends to use the embryo herself in IVF treatment.
- The donor has given consent for continued storage.

Decision

The committee agreed to **approve** this application for 1 year.

Actions

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

20. Application E16/57 to Extend Storage of embryos

The committee considered this information in relation to the *Guidelines for Extending the Storage Period of Gametes* and the principles of the HART Act 2004.

Issues discussed included:

- The applicants wish to explore the option of surrogacy to add to their family. They are actively looking for a surrogate.

Decision

The committee agreed to **approve** this application for five years.

Actions

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

21. Application E16/58 to Extend Storage of embryos created with donor sperm

The committee considered this information in relation to the *Guidelines for Extending the Storage Period of Gametes* and the principles of the HART Act 2004.

Issues discussed included:

- The donor in this application has consented to extended storage for two more years.

Decision

The committee agreed to **approve** this application for two years.

Actions

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

22. Application E16/59 to Extend Storage of donor sperm

The committee considered this information in relation to the *Guidelines for Extending the Storage Period of Gametes* and the principles of the HART Act 2004.

Issues discussed included:

- The applicants have a child and would like to have another child and full-sibling using this donor sperm. The donor has consented to extended storage up to five years.
- The applicants have stated original storage as May 2006 and the clinic letter states November 2006. ECART requests confirmation of the date with the clinic to ensure that it is lawfully approving extended storage.

Decision

The committee agreed to **approve** this application for five years.

Actions

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

23. Application E16/60 to Extend Storage of embryos

The committee considered this information in relation to the *Guidelines for Extending the Storage Period of Gametes* and the principles of the HART Act 2004.

Issues discussed included:

- The applicants have requested an extension of 1 year but the committee agreed that an extension of two years would be more appropriate.

Decision

The committee agreed to **approve** this application for two years.

Actions

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

24. Application E16/61 to Extend Storage of donor sperm

The committee considered this information in relation to the *Guidelines for Extending the Storage Period of Gametes* and the principles of the HART Act 2004.

Issues discussed included:

- The applicants have children and want the same donor to have a full sibling for their children.
- The donor has consented to extended storage for up to five years.

Decision

The committee agreed to approve this application for five years.

Actions

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

26. General business (discussed on 15 September 2016)

The committee acknowledged a letter received from Fertility Associates CEO thanking ECART for its 23 August 2016 letter. The letter from Fertility Associates stated that the issues raised in ECART's letter will be discussed at FA's monthly meeting. The letter also requested that in future ECART communicate general issues through the CEO for discussion with FA as a whole.

ECART agreed that it will write to ACART about the post-humous use of sperm guidelines expressing ECART's view that they need to be reviewed and, as part of this review, that it is important that there is consultation in order to reflect the current public opinion. In the same letter ECART agreed to state its view that there is a need for the human reproductive research guidelines to be refreshed to make them more consistent with health and disability research ethics guidelines and more specific. ECART agrees that the guidelines are outdated and need to be revised. The third issue that ECART would like to raise in the letter is to request that ECART look at the social media issue and what constitutes advertising and provide advice to ECART about this as it is something that comes up frequently.

27. Conclusion of meeting

The committee confirmed the next ECART meeting date of 3 November 2016. Iris Reuvecamp will open the meeting.

The committee confirmed the next ACART meeting date of Friday, 14 October 2016. Iris Reuvecamp will attend.