Minutes of the Ninety-fourth Meeting of the Ethics Committee on Assisted Reproductive Technology

12 April 2022

Held via zoom on 12 April 2022

In Attendance Iris Reuvecamp Jeanne Snelling Angela Ballantyne Mania Maniapoto-Ngaia Jude Charlton Mike Legge Emily Liu Analosa Veukiso-Ulugia Richard Ngatai	Chairperson Member Member Member Member Member Member Member Member
Simon McDowell	Medical Expert Adviser
Karaitiana Taiuru	ACART member in attendance (until 2pm)
ECART Secretariat	
Apologies Tepora Emery	Member

1. Welcome

The Chair opened the meeting and welcomed all in attendance. The Chair invited ECART to consider reintroducing the agenda item of members opening a meeting with a brief comment on issues or topics that are of interest in the fertility space. ECART agreed that members who are interested in contributing to the next (and any subsequent) agenda, could contact the Chair and Secretariat in between meetings.

Mike Legge offered to submit a publication on how it may soon be possible to whole genome sequence a single cell from an embryo, which could change the way people test embryos, as DNA analysis is becoming less costly. The technology is rapidly changing. Being able to sequence a whole genome from a single cell is a significant change in the fertility space.

The Chair queried whether ACART might also be prepared to have a standing item on ECART's agenda for updates on ACART work. It was agreed ACART would be open to this and would follow up with ECART about the possibility of ACART/ECART Chairs meeting in between meetings also.

2. Conflicts of Interest

3. Confirmation of minutes from previous meetings

The minutes from the 25 February 2022 meeting were confirmed.

4. Application E22/057 for surrogacy involving an assisted reproductive procedure with donated eggs

Mania Maniapoto-Ngaia opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

- The intending parents are a same sex couple using embryos using the one of intending parent's sisters' eggs for the embryo.
- The egg donor has completed her family, is aware of the medical risks and processes involved having already been through IVF for her own family.
- The egg donor and her partner understand that on-donation is now permitted but have expressed they have no interest in this and are aware that decisions around embryos and their storage lies with the intending parents.
- The birth parents have children and consider their family complete. The birth mother has a medical condition that will need to be monitored for gestational diabetes but otherwise has an unremarkable birthing and medical history. The risks of carrying a surrogacy pregnancy have been outlined and discussed with her and her partner and pregnancy and birth plans and the birth mother's rights in relation to decision making about the pregnancy have also been discussed during the sessions that have taken place as part of this application. She has acknowledged the ante-natal and post-natal risks associated with a surrogate pregnancy and the ways in which they might be managed.
- The intending parents have a good social support network and intend to be open with their family about the surrogacy arrangement and many members of their supporting family have been informed of the situation but there will be more information shared once a pregnancy is confirmed.
- The intending parents have agreed to support the birth mother's children with provision of resources for counselling should this be necessary and wish for a relationship to form between the birth mother's children and any children resulting from the surrogacy.
- The intending parents plan to be open with the child resulting from the surrogacy about their conception story and the role the surrogate played.
- The intending parents have stated they may post to social media about the pregnancy should it eventuate however, the privacy of those parties involved will be maintained and protected.
- The intending parents plan to adopt the child and have received approval for an adoption order in principle from Oranga Tamariki.
- Testamentary guardianship has been agreed.
- Should there be a separation of the intending parents there will be a discussion around this, and custody will be arranged if this occurs.

- The birth parents are understanding of the legal processes involved in the relinquishment of the child to the intending parents and plan to do so as soon as medically possible and understand that the process of adoption can take up to 6 months.
- All legal matters have been understood by all parents and donors including the HART act.

The Committee agreed to **approve** this application with the recommendation that the birth mother's 11-year-old child receive independent counselling.

Actions

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

5. Application E22/058 for surrogacy involving an assisted reproductive procedure with donated eggs

Angela Ballantyne opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

Issues discussed included:

- The intending parents and the birth parents have a long-standing relationship, and the intending parents describe the close and familiar relationship.
- The birth mother has indicated that she does not wish to share a genetic link with the child resulting from the arrangement but is happy to carry the pregnancy.
- The egg donor was found and engaged online and there were discussions of a reciprocal relationship with the intending parents potentially donating sperm in the future.
- The birth mother and partner have children and consider their family complete. The birth mother was noted to have moderate post-natal depression with her own children that has been addressed and a plan made for such an occurrence in the future. Other than that, her medical history and birth history were uncomplicated.
- The birth mother's children have not yet been told or received counselling on the arrangement.
- A II parties have plans for ensuring the children are informed and the relationships with the future baby are managed well.
- The intending parents plan to adopt the child and have received approval for an adoption order in principle from Oranga Tamariki.
- Testamentary guardianship has been agreed.

Decision

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.

6. Application E22/055 for surrogacy involving an assisted reproductive procedure with donated sperm

Jeanne Snelling opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

- The intending parent is a single woman wishing to have a child but is unable to carry a pregnancy as she has had renal failure as a child and has received two kidney transplants.
- The risks associated with an IVF cycle to collect the intending parent's eggs has been discussed with the intending parent.
- The birth mother has one child and is the sister of the intending parent and whilst having had a history with two medical conditions and some post-natal depression with her own child her medical and birth history is otherwise considered uncomplicated. She is aware due to her age of the risks associated with her acting as a surrogate and it is recommended that she be prescribed aspirin in her second trimester and that she receive specialist ante-natal care during the surrogacy.
- The sperm donor is a clinic donor who has completed his family and has donated out of altruism. He has no notable medical history except that he has reduced sperm motility which has been accounted for by the plan to use ICSI when creating the embryo.
- The intending mother lives with her mother who is a key support person and intends to help the mother with the pregnancy and afterwards.
- The relationship between the intending mother and the birth mother is close as they are sisters, and the birth mother is considered a loving aunty in the lives of the birth mother's own children.
- The birth mother intends to look after the child if anything happened to the intending mother.
- The intending parent has agreed to have pre-implantation genetic screening on the embryos.
- The birth mother and her partner have not specified a plan for counselling for their daughter of the birth partner from a previous relationship.
- There is planned ongoing contact between the families.
- All parties intend to be open with any potential child.
- All legal matters including compensation, the HART act and adoption were discussed with all parties and noted as being understood.
- The intending mother plans to adopt the child and have applied for an adoption order in principle from Oranga Tamariki.

The Committee also discussed the following:

- Whether the cause of the intending mother's renal failure is genetic, and if it is, whether appropriate counselling has been provided to the Intending Mother (including the possibility of PGD if it involves a monogenic condition given PGS is already being proposed
- It was unclear what the health status of the intending mother was in light of what it appears to have been a second recent transplant there is no discussion of this in the reports and the letter from the renal physician does not mention this
- At the age of 42, the chances of successfully conceiving a child are significantly reduced. It is unclear whether the intending mother is aware of this.
- The Committee considers that it would be appropriate for the birth mother to be reviewed by an obstetric physician
- If a pregnancy is established, the Committee would expect the birth partner's 12-year-old child to undergo independent counselling
- Testamentary guardianship was not specifically referenced in the legal reports. While it was noted that the birth parents would take care of any child if anything happened to the intending mother, such arrangements ought to be formalised

Decision

The Committee agreed to **defer** this application pending further information relating to the outstanding matters outlined above.

Actions

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

7. Application E22/056 for surrogacy involving an assisted reproductive procedure

Mike Legge opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

- The intending parents have a 3-year-old child who was conceived naturally. Since the birth of their child, the intending mother has a history of unexplained infertility. She has a number of embryos that have been transferred without success and PCOS has been confirmed.
- The intending parents have been informed as to the birth mother's rights and agree to defer to the birth mother's preferences and choices with all aspects of the pregnancy. The intending parents have been given legal advice and have been made aware of the adoption process and proceedings with Oranga Tamariki.
- The intending parents are aware of the storage conditions and the laws around this.
- Testamentary guardianship has been agreed upon.
- The birth mother has children and considers her family complete. She is the sister of the intending father and they have regular contact that would not

change as the result of the surrogacy arrangement. She has had no complications with her births and her medical and birthing history are considered uncomplicated.

- Both parties have been open with their family and some members of their support network with respect to the surrogacy arrangement and plan on informing any child of the arrangement should one result from the surrogacy but will not post anything to social media.
- Both families intend on an extended family relationship between their children and the birth mother intends to tell her children of the arrangement once pregnancy is confirmed at 9 weeks gestation.
- The birth parents are aware of counselling support. All legal aspects of the surrogacy and the adoption requirements have been understood.
- The intending parents plan to adopt the child and intend to apply for an adoption order in principle from Oranga Tamariki.
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Decision

The Committee agreed to **approve** this application subject to approval in principle of an adoption order from Oranga Tamariki.

Actions

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

8. Application E22/059 for traditional surrogacy arrangement with within family gamete donation

Iris Reuvecamp opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

- This is a traditional surrogacy, and therefore does not require ECART approval (the Guidelines require that any surrogacy that involves an assisted reproductive procedure requires approval from ECART, but a traditional surrogacy, using a surrogate and her own eggs, is an established procedure as it falls within the definition of artificial insemination.
- There is a within family donation element to this intended arrangement. Because the intended arrangement will involve the use of donated eggs, and the donor falls within the definition of a family member (and does not fall within the definition of a sister or cousin of the patient), an application does need to be made to ECART, and the ACART guidelines as a whole apply.
- The intending parents were both born offshore and moved to New Zealand as children with their families of origin. The couple met as young adults. After having difficulty conceiving naturally, they underwent extensive fertility treatment including multiple rounds of IVF, which were unfortunately unsuccessful. Due to the intending mother's age and fertility history, the couple were advised that using a surrogate and egg donor would give them the best chance of conceiving.

- The surrogate is married to the intending father's cousin. The two male cousins grew up together, and have maintained a very strong bond as adults, which the men describe as akin to "brothers". The cousins' wives are also close and throughout their difficult fertility journey, the intending parents have shared their struggle to conceive with the birth parents.
- The counselling sessions have addressed the surrogate's motivation for her offer and describe the birth parents agreeing to help the intending parents after completing their own family and with the knowledge of the intending parents' need for a surrogate and egg donor. Discussions were initially focused on the birth mother solely as surrogate, with the intending parents utilising a clinic egg donor. However, after learning of the long delay they would face to access a clinic egg donor, the surrogate then offered to donate her eggs also. The couples have taken time to consider the implications of such an arrangement for their relationships, eventually arriving at the conclusion that it will only enrich their connections with each other.
- There are no concerns here about undue influence, or about the health and wellbeing of any potential offspring or the birth parents three children. Affected patients have been counselled and the relationship does safeguard the wellbeing of all parties including any offspring. The general requirements have been met, as have the counselling and consent requirements. Legal advice has been sought and independent medical reports obtained, and the parties understand the health implications of the procedure.
- In this regard, the birth mother underwent a tubal ligation following the birth of her third child. She experienced a 4th degree tear with the birth of her first child and does not report any psychological trauma as a result of this. She underwent caesarean sections for her subsequent deliveries and had a post-partum haemorrhage with her third child. She would plan a caesarean section for a delivery from this surrogacy. The birth mother suffered hyperemesis with all of her pregnancies. She managed this through the use of medication and was also hospitalised on two occasions requiring IV fluids. She is aware that there is a high likelihood that she would experience hyperemesis with a further pregnancy, and she has considered the impact that this would have on her world, personal commitments and mental health. The birth mother is of the opinion that she could manage this with the support of her obstetric team and making an early plan involving medication. She discussed this requirement with the intending parents as it was important to her that they felt comfortable with her taking medication throughout pregnancy. ECART was satisfied that the parties have been well counselled about the issues throughout the process and appropriate management of risks has been discussed and agreed on.
- ECART was satisfied that there are no concerns in relation to coercion, and that everyone has been counselled appropriately and the relationships safeguard the wellbeing of all parties including existing and potential children. ECART was satisfied that the general, counselling and consent requirements have all been met and that all parties understand the health implications of the procedure. Oranga Tamariki have given provisional approval for an adoption order.

The Committee agreed to **approve** the within family gamete donation aspect of this application having considered the guidelines that related to this aspect. ECART's

recommendation in relation to the traditional surrogacy having reviewed it in line with ACART's guidelines in full would be that it would approve this application.

Actions

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

9. Application E22/060 for Surrogacy involving an assisted reproductive procedure

Analosa Veukiso-Ulugia opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

- The intending mother and father have no children and as yet have no existing embryos.
- The birth parents have children and consider their family complete.
- The birth mother has had uneventful pregnancies and deliveries, but the reports note a small risk of CMV infection occurring during pregnancy and a small risk of infection in the baby. The Committee noted that a reactivation of an infection during pregnancy carries a much smaller risk than a primary infection in pregnancy and the risk to the foetus is negligible. Other than that, the birth mother is considered medically fit and well to carry a surrogate pregnancy. The birth mother has disclosed her mental health history, which is being managed with her health care team and they have an appropriate process in place to care for her.
- The birth mother and intending mother are sisters with a close relationship that extends to the rest of their family and planning for care during pregnancy has been undertaken.
- The intending mother has a history of dilated cardiomyopathy which subsequently led to renal failure that necessitated a kidney transplant. The intending mother also suffers from hypertension diabetes and the medications necessary to maintain her health have led to the recommendation to pursue surrogacy.
- The Committee discussed whether all parties ought to be aware that the dilated cardiomyopathy may be heritable. The Committee noted that a specific gene defect is needed to do PGD and this condition is multifactorial – it is not possible to deselect the gene. It was also noted that it is highly likely that the issue of the condition being heritable would have been raised with the couple in advance if this was necessary.
- The Committee discussed whether to seek further information from the intending mother's specialist to ascertain how well she currently is and the future risks to her health, as well as what support structures are in place to ensure the child continues to be well cared for. The Committee agreed it would only seek further information about the support that would be available for the child in the event that the intending mother's health deteriorates.

- The birth mother has been informed that any decisions about termination of pregnancy will be hers to make. However, she would like to discuss any options with the intending parents prior to termination.
- The birth parents intend to be open with their own children about the intended arrangement and are aware counselling services are available. They have no intention of posting anything to social media.
- All parties intend to be open with any resulting child as to the nature of the arrangement and are aware of counselling if it is needed and the legal requirements related to adoption and surrogacy.
- The intending parents have agreed to pay for the birth mother's life insurance premiums at the point of treatment through to a few months postpartum. In the counselling reports the intending parents are stated to have chosen the birth parents to be testamentary guardians of the child in the unlikely event that the intending parents are not able to care for the child and that this arrangement has been agreed on with the birth parents. The legal reports note that they did not have wills in place at that point in time and the Committee agreed it would like confirmation that specific legal arrangements have been made relating to testamentary guardianship.

The Committee agreed to **defer** this application pending further information about the arrangements in place to care for any resulting child in the event the intending mother's health deteriorated, as well as confirmation that specific legal arrangements have been made relating to testamentary guardianship. ECART agreed to consider the response in between meetings.

Actions

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

10. Application E22/061 for embryo donation for reproductive purposes

Emily Liu opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

Issues discussed included:

 Due to fertility issues, the donating couple created embryos and used IVF. Given their own experience with IVF and ART the donor couple decided to donate their embryos.

The donor party consider their family complete and have been transparent with their children about the donation process and are aware of the counselling available to the effect.

• The donor father was genetically screened and returned as a carrier for galactosemia. The donor mother was not a carrier so there is no risk to offspring.

- The recipient parents are unable to conceive their own child due to tubal disease and low sperm viability. They have already attempted ART however there was no success in this procedure.
- The recipient mother does not have a notable medical history and has been counselled on the increased risk during pregnancy due to her maternal age. The recipient mother has been advised to seek obstetric care during the pregnancy.
- The recipient mother has a history of depression. However, she takes medication and is well supported. She has a good awareness of self and her condition and does not feel that this will affect the progress of this arrangement.
- Both parties have agreed to be open with any resulting child from this donation and are aware of counselling in the event of dispute.
- Both parties were counselled as to termination of any resulting pregnancy, the HART act, embryo storage, disposal and withdrawing consenting and were deemed to be understood by all parties involved.

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.

11. Application E22/062 for Surrogacy involving an assisted reproductive procedure with donated eggs

Mike Legge opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

- The donor couple have embryos created through IVF treatment that they wish to donate to the recipient couple. If this embryo donation is successful there would be full genetic siblings in two families and no on donation of any remaining embryos would be permissible under current guidelines.
- The recipient couple have a long history of infertility and have had unsuccessful IVF treatment using their own gametes. Due to previous unsuccessful treatment and the maternal age of the recipient woman, they would wish to continue treatment using donated embryos.
- The medical report for the recipient woman is supportive of her ability to carry a pregnancy and pregnancy care and specific risk factors for her have been discussed and a recommendation made that she be referred for specialist obstetric care once a pregnancy is established.
- One of the donors has tested as a carrier for a condition and, the recipient couple have been made aware that any potential child may also be an unaffected carrier for the condition and the potential consequences of this.
- The donor couple's motivations for donation have been discussed in counselling sessions. They do not wish to discard the embryos due to the effort and emotion that went into creating them and their preference is to give the embryos a chance

at life. They have chosen the recipient couple to donate to as they believe they have shared values. The couples met in 2021 and they have since established a relationship and continue to nurture their relationship and would expect it to continue.

- The donor couple are committed to being open and transparent with their own children about the intended donation to help them understand their connection with any child/ren born to the recipient couple. It is important to the donor couple that the potential child/ren know where they can access information about their biological heritage.
- The donor couple have been counselled about their rights in relation to the embryos including that after transfer to the recipient woman they have no legal or parental rights.
- One of the donors is Māori and has declared intentions to provide information (whakapapa) and cultural guidance to any resultant child – they see this as being very important especially in relation to identity development. The recipient couple have declared they are prepared to support any resultant child to understand their Māori heritage and link with their whakapapa.
- The recipient couple have an adopted (at birth) child who is of different ethnicity to them, and the donor couple have witnessed how the recipient couple have embraced their child's cultural heritage and are committed to helping the child have a connection to this. The recipient couple desire a sibling for their child and feel that their existing child and a child born of this arrangement would share similar conception stories providing better balance for their family.
- The recipient couple describe having made peace with not having a genetic link to their children. They have a secure and loving bond with their first adopted child and consider that family is more than genetics.
- It is evident throughout the counselling reports that openness and transparency with all children is valued.
- The Committee noted that it wasn't clear from the reports what the fertility related issue was, in particular for the recipient man, and why it is not possible to use his gametes in future fertility treatment. This is relevant as the Committee is required to be satisfied that embryo donation is the "best or only" opportunity for the couple to have a child. ECART noted that this intended arrangement might be the best or only opportunity for the couple to have a vailable now and the process of finding an egg donor could be a lengthy one.
- The challenges of maintaining a child's connections when cultures of origin differ was discussed by the Committee.

Decision

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.

12. Application E22/063 for within family sperm donation

Jude Charlton opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

Issues discussed included:

- The intending parents are a same sex female couple, and they require a sperm donation for pregnancy. ECART approval is required as the donation is a within family donation.
- The gamete donor has children with their partner and the couple consider their family to be complete. The donor has colour-blindness but is otherwise healthy. The recipients are aware of this.
- The donor undertook genetic carrier testing. The result showed 5 positive carrier statuses for autosomal recessive disorders. The recipient woman tested for the same conditions to ensure there was no crossover between these conditions so the child would be unaffected.
- The recipient woman's medical history is considered uncomplicated with no conditions of note.
- The recipient parents intend on having one child with the possibility to have a second in the future either using the recipient mother's eggs or the partner's eggs.
- The recipients are aware that in the event of potential termination of the pregnancy the recipients do not need to consult the gamete donor.
- Counselling has been undertaken and both parties are willing to be open with any resulting children. The dynamics of the relationship between the children has been satisfactorily discussed.
- Both parties have been counselled on the HART act, gamete storage, the withdrawal of consent and the process of conflict resolution should this arise. They are aware ongoing counselling is available should this be necessary in the future.

Decision

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.

13. Application E22/064 for creation of embryos from donated eggs and donated sperm

Analsoa Veukiso-Ulugia opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

Issues discussed included:

• The intending mother has had previous fertility treatments without success and her specialist is of the view that the outcomes are due to her advanced maternal age and the use of donated eggs will improve her chances of starting a family.

Her specialist is also of the view that she is medically fit and well to carry a pregnancy should treatment from this intended donation be successful.

- There is a within family aspect to this application as the egg donor is the intending mother's cousin. They describe a strong friendship that continues in adulthood. The within family aspect of the application is an established procedure (because the egg donor is the intending mother's cousin), and ECART approval is therefore not required on this basis. However, ECART approval is required because the embryos will be created from donated eggs and donated sperm.
- The egg donor will see herself as a social aunty and also intends to be open with the potential child about the role she played in the child's conception. Plans for future contact between the parties have also been considered in the context of the intending mother and egg donor relationship and in the broader context of a wider supportive family.
- The motivations for the donation were discussed during counselling sessions. The egg donor knew of the challenges the intending mother has had on her fertility journey and made the offer to help her start her own family. Her wider family have experiences of donor conception and are supportive of the intended arrangement.
- The intending mother and egg donor have thought about and agreed plans for how the intending mother can support the egg donor and her family when the egg collection treatment takes place. Plans and care for the storage, use, and discarding of embryos created have also been well considered as well as ondonation of any remaining embryos.
- The egg donor is well-informed and accepting of the risks of donation and the intending mother demonstrates a well-informed, considered and clear understanding of the implications of donor conception and donor conceived children in single parent families who have chosen donor conception.
- The egg donor and her partner consider their own family to be complete. The sperm donor is an altruistic clinic donor who does not have children of his own. He is a foreign national currently living in his country of origin, but he plans to live between two countries and, he is open to having contact with a child in future. The intending mother has with the help of clinic counselling services, made a first contact to start their relationship.
- All parties know that the intending mother has legal rights to make decisions about the pregnancy and once the child is born is the child's legal parent.

Decision

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.

14. Application E22/065 for post-humous use of sperm

Iris Reuvecamp opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo*

donation, the use of donated eggs with donated sperm and clinic assisted surrogacy, and the principles of the HART Act 2004.

- The issue ECART needs to decide on in this application is whether the donor gave consent to the posthumous use of his sperm.
- The legal framework and guidelines within which ECART must consider this application were set out.
- The HART Order provides that a procedure is not an established procedure if it involves the use of sperm that was collected from a person, who has since died, who did not give consent to the specific use of the sperm before that person's death.
- The reason this application is before ECART is because there is no evidence that the donor gave consent to the specific use of his sperm by the applicant.
- ECART is required to consider this application in accordance with current guidelines. The NECAHR guidelines dated February 2000 have been adopted as guidelines by ACART since the HART Act took effect. They set out the need for a cultural, ethical and legal focus.
- In relation to the ethical focus, NECAHR/ACART considers key ethical principles include the balancing of benefits and risks for all parties and prioritising of needs, benefits and risks for children specifically, issues of consent in relation to information, coercion and autonomy, vulnerability of participants, privacy considerations.
- In relation to the legal focus, NECAHR/ACART considered the following issues: that the potential child should be considered in any decision made about the use of gametes, whether gametes can be owned, and what form of property they might constitute, inheritance rights for children conceived posthumously, the significance, before death, of consent given to posthumous use of gametes, human rights legislation in New Zealand.
- The Guidelines also look at what Consent forms must include as to what is to happen should the sperm donor die leaving sperm in storage at a clinic/service. The applicable situation before ECART is that of sperm placed in storage prior to medical intervention. The Guidelines provide that, at the time of collection, two options ought to be provided to the person in the event they die leaving sperm in storage - consent is given for the disposal of the sperm or for use by a specified person within a specified timeframe.
- The applicant, his partner, has stated that the consent is not reflective of the consent he subsequently gave her, for her to use his sperm.
- The soon to be published ACART guidelines which are intended to replace the NECAHR guidelines provide that ECART must be satisfied that the person consented to the specific use of gametes in the event of their death, the consent is for use by a specific person/s who will be the intending parent/s, neither the donor nor the intending parent/s have been subject to undue influence, the donor and intending parent/s considered the potential social and psychological risks to the child/ren and demonstrated why the risks are justified, and consent to posthumous use is valid taking into account the time since consent was given and any changes in circumstances since an individual consented to posthumous use.

- In the case, there is evidence of consent provided at the time the sperm was stored around 10 years ago that the sperm be disposed of in the event of his death, which the applicant says has been superseded based on discussions the couple had when he was alive.
- The applicant says that in the 18 months prior to his death, they talked about having children and she also engaged with clinic services to assess her chances of conceiving with her gametes. She stated they agreed they would try to conceive naturally first before considering using the option of his stored sperm. She recalls a conversation they had not long before his death when the possibility of her using his sperm in the event he died was raised by her. She describes this as a poignant moment in retrospect as he agreed to her using the stored sperm.
- The applicant had a number of consultations with a fertility services provider in the months prior to his death. The notes taken at the time reflect that she was aware of his stored material collected prior to medical treatment but was wanting to assess her fertility and options for preserving that at the time until they were both ready to commit to starting a family. Notes from a further consultation after his death did not make reference to the conversation the couple had when he was alive about his partner using the stored gametes in the event of his death. Notes from counselling sessions also note honest discussions between the counsellor and the applicant prior to the donor's death about his hesitancy in starting a family with her and a recent change of heart to commit to this with her. Notes from a counselling session held soon after his death note that his sperm was still stored but do not detail any discussion around the initial consent nor the conversations the couple had when he was alive about the possibility of her using the sperm.
- A planned sperm test prior to the donor's death wasn't seen as urgent and was planned to be done at a later stage.
- A letter from the applicant's long-standing counsellor sets out their client patient history and her counsellor states that in her view, the applicant has given an honest account of their plans to have children together.
- The deceased man's parents are supportive of the applicant using their son's stored sperm in fertility treatment.
- The sole question for ECART is whether it considers the man gave informed consent to posthumous use of his stored sperm.
- ECART considers that there is a distinction between a person wanting to have children in the context of a relationship and agreeing and planning that, and the posthumous use of gametes.
- ECART agreed that since the original consent was given, there has been a significant change in circumstances as he was in a committed relationship with the applicant and was considering starting a family with her.
- The Committee discussed whether it could be satisfied that he had given informed consent to the posthumous use of his sperm, which in the context of this application, hinged upon the conversation the applicant described that occurred a few weeks before his death.
- The Committee agreed that the applicant's account of their conversation prior to his death would not meet the criteria for evidence of valid consent to use his sperm after death

- ECART noted that the draft ACART guidelines that are soon to be issued state that the criteria ECART needs to apply in such circumstances are that a person consented to specific use after death, that the consent is to a specific person, that they considered and understood the potential social, psychological risks to the child/ren and demonstrated why the risks are justified and that consent is valid.
- ECART was not satisfied that there was evidence of consent that would allow ECART to see that he had considered what use after his death would mean for him, her and the potential child/ren.

The Committee agreed to **decline** this application because the evidence provided could not satisfy the requirement for informed, valid consent.

Actions

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

15. Application E19/050 for surrogacy involving an assisted reproductive procedure

Mike Legge opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

Issues discussed included:

- ECART approved this application in 2019 and the surrogacy arrangement has been successful with a child born and the adoption of the child by the intending parents.
- The same applicants are seeking continued approval for a further three years to try for a sibling for the intending parents' child.
- The surrogate has offered to be a surrogate for the intending parents again and is considered medically well.
- Their previous arrangement went smoothly, there were no complications medically with the pregnancy or birth, it was a positive experience for everyone and the parties continue to be friends.
- The surrogate and the intending parents have discussed and agreed ways to put more practical support in place for the surrogate this time around should she need this.

Decision

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.

16. Application E22/067 for embryo donation for reproductive purposes

Jeanne Snelling opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

- This application is for the donation of embryos that were created with donor eggs and the donor man's sperm to the recipient woman for use in treatment to have a child and a sibling for her existing child who was also donor conceived.
- The donor couple have a child born from the embryos and two older children from the donor man's previous relationship and, consider their family to be complete.
- The egg donor has children and considers her family to be complete. She is aware of the intended donation and is happy for the recipient woman to contact her and to give information if requested. Her own children know that she is a donor and that they have a half-sister in the donor couple's family. Socially their relationship is that of cousin.
- The egg donor's medical history includes some maternal family history of a medical condition of which there has been no concern to the egg donor to date.
- There are several embryos in existence and the donor couple have agreed to donate the embryos one by one to the recipient woman as they wish to know when the embryo transfers are taking place. They would also want their youngest child to know any child born of this arrangement as the children would be full genetic siblings, they would tell their child of this from a young age, and they envisage meeting once or twice a year.
- The donor couple have noted in their counselling sessions that they don't want any embryos destroyed as they would consider that immoral and they would wish for someone else who has experienced infertility to have a child. They understand that the recipient woman would have legal rights to make decisions during her pregnancy and as a parent of any resulting child.
- The recipient woman would like to have one more child and has discussed this with the donor couple. There may be remaining embryos if she conceives in the first or second transfer which could hold implications for the donor couple who consider that discarding embryos would be immoral.
- The donor couple chose the recipient woman from an online forum and have been building a relationship with her for around a year at the time the application was submitted. They met in person last year. They wish to have ongoing communication with her.
- A child born from this donation would have a number of half sibling relationships and a full sibling relationship with the donor couple's children.
- There are resources available to explain those connections and family ties for the child.
- The recipient woman is aware she has created her family outside of social norms and she has received some negativity and judgement about being a single parent of a donor conceived child. She has declared intentions to nurture connections with the various parties and wider family of the potential child and has thought through how this contact might look and work. She has a supportive family herself who live in close proximity to her. She understands she will be

the legal parent of any child born and, she has agreed testamentary guardianship within her family in the event she is unable to care for the child.

• The donor couple have said they would be happy for the recipient woman to make decisions about non-viable embryos. There doesn't appear to have been discussion about what would happen if there are remaining viable embryos and the recipient woman has a child.

Decision

The Committee agreed to **approve** this application noting that if the recipient woman doesn't have children any remaining embryos can be on donated. In the event she does have a child and there are remaining embryos, they cannot be on donated.

Actions

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

17. Reconsideration of request to continue approval for application E19/047 for surrogacy involving an assisted reproductive procedure

Iris Reuvecamp opened the discussion for this application. The Committee considered this application in relation to the *Guidelines for family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic assisted surrogacy,* and the principles of the HART Act 2004.

Issues discussed included:

- ECART considered this request at its February meeting and approved the continued treatment up until July this year when the first term of three years is set to finish.
- The clinic has requested three years. ECART agreed there is no reason not to grant the extension for a further three years rather than to July this year to allow for treatment to continue to establish a pregnancy.

Decision

The Committee agreed to **approve** this application for three years post July 2022.

Actions

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

18. Consideration of extended storage applications

Meeting close

Confirmation of next meeting on Thursday, 9 June 2022.

Confirmation of ECART member in attendance at next ACART meeting on 5 May 2022. Richard Ngatai to attend.