Minutes of the one hundred and sixth Meeting of the Ethics Committee on Assisted Reproductive Technology

20 June 2024

Held in person and online on 20 June 2024

In Attendance

Jeanne Snelling	Chairperson
Analosa Veukiso-Ulugia	Member
Angela Ballantyne	Member
Annabel Ahuriri-Driscoll	Member
Emily Liu	Member
Jude Charlton	Member
Lana Stockman	Member
Mania Maniapoto-Ngaia	Member (until 10.45am)
Mike Legge	Member
Peter Le Cren	Member
Richard Ngatai	Member
Simon McDowell	Member

Catherine Ryan ACART member in attendance

ECART Secretariat

1. **Welcome**

The Chair opened the meeting and welcomed all in attendance.

2. **Karakia**

Richard Ngatai led the Karakia.

3. **Conflicts of Interest**

E24/127 - Dr Emily Liu declared a conflict of interest and did not take part in the decision making for this application.
E24/128 and E24/136 – Dr Simon McDowell declared a conflict of interest and did not take part in the decision making for these applications.

4. **Confirmation of minutes from previous meetings**

The minutes from the 11th April 2024 and 17th May 2024 meetings were confirmed.

5. **Application E24/125 for embryo donation for reproductive purposes**

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 parent is a single woman requiring sperm donation to begin her family. She also requires egg donation due to poor responsiveness to IVF stimulation and diminished ovarian reserve. Given the difficulty obtaining both an egg and sperm donor, embryo donation provides the best opportunity for the intending parent to have a child. The Committee noted the long wait time for egg and sperm donors and, given this and the intending parent's advanced maternal age, agreed that embryo donation was the best opportunity for her to have a child.
- The intending parent and donor couple got to know each other on a donor forum and keep in touch regularly. The donor couple wish to donate their remaining embryos, that were created for their own IVF treatment, to the intending parent as they consider their own family to be complete.
- The medical report for the donor couple notes that the female donor has a family history of a genetic condition and the donor couple had genetic counselling for this prior to beginning their own fertility treatment. The male donor had a normal carrier test and the risk of having an affected child is very low. The donor couple have shared this information with the intending parent.
- The intending parent has been informed of the increased risks of carrying a pregnancy due to her advanced maternal age and elevated BMI. She is working on lifestyle changes to mitigate these risks before she would proceed with an embryo transfer. The intending parent has health/mental health conditions which are well managed.
- While the family of the intending parent do not live in New Zealand to offer her support during a pregnancy, she has a good support network of friends who have offered to help her during this process.
- As for any ongoing relationship between the intending parent and donor couple, both parties consider that they will have a life-long relationship with one another and their children. To support the wellbeing of any resulting child, the intending parent plans on being open with the child when they are young about their family story and has received information about the needs of donor conceived children around information sharing.

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 E24/126 for the creation of embryos from donated eggs and donated sperm

Lana Stockman 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:

- In this application, a single intending parent who has had numerous fertility treatments using her own gametes without success, wishes to use donated eggs and sperm to create embryos for her use in fertility treatment. Medical advice is that given her age, her chance of a successful IVF treatment is around 3% and the use of donated gametes offers her the best opportunity to have a child. On the basis of this advice, the Committee was satisfied that the intended arrangement offers her the best opportunity to have a child.
- The egg donor's offer to donate her eggs to the intending mother was made in the context of an established friendship that has spanned time and more recently geographical distance; she has completed her own family and wishes to help her friend, the intending mother, complete her family. The sperm donor is a clinic donor whose donation has been used by the intending mother in past fertility treatment with her own eggs.
- The intending mother has a history with her clinic counsellor given her fertility journey to date and has had further implications counselling for this planned assisted reproductive procedure. Her counselling has covered the social support available to her and her child, which is strong through her family and friends' networks. Counselling has also covered her treatment, pregnancy and birth plans.
- The intending mother has one child at the time this application was submitted. Her child was conceived without fertility treatment. She would like to have a sibling for her child and believes that a sibling will be good for their well-being. The intending mother's existing child is Māori and counselling reports describe that the potential child will also be raised with other whānau in Te Ao Māori values and culture.
- Her medical report notes that she is medically well to carry a pregnancy and she has had the risks of carrying a pregnancy at an advanced maternal age, noted and discussed with her. The report also notes her general medical history and, that a medical condition she carries was not an issue in her previous pregnancy.
- The main medical issue raised in reports for the egg donor was in relation to genetics. She has had counselling sessions with a genetic counsellor and the information from these sessions has been shared with the intending mother. The genetic counsellor's report included with the application noted that it is difficult to quantify risk in this case, given the mix of genetic and environmental factors that may contribute to a child having her conditions. Another condition is not considered to be familial/genetic and hence "low risk" to a potential child. IP has been informed of ED's family medical history and that ED saw a genetic counsellor to discuss. The implications of having a child who has the condition have been addressed in counselling sessions.
- The egg donor has some apprehension around the egg collection process but is still happy to proceed with the treatment for one round if the Committee approve this application.
- Information sharing/access and HART Act requirements and intentions around a child born of this arrangement (and existing children), having access to this information have been discussed during counselling sessions. The parties know that their information will be on the HART register for a child to access once they are 18 years old. All parties have declared intentions to be open with

the child and to be available to the child from a young age. The intending mother is part of a network that shares resources about how to talk with children about their conception stories. The egg donor is of the view that the relationship she and the intending mother share will help ensure the well-being of all including their existing children.

- The sperm donor and partner now have children of their own since his donation was made. He has been made aware of the number of families using his donation and the number of children born. He has not told his own children that he is a donor but has declared intentions to do so in future.
- Counselling reports note discussion of the rights of the gamete donors in relation to use of their donations to create embryos. They know that once the embryos are created decisions about fertility treatment, pregnancy, and birth and, subsequently parenting decisions, will be the intending mothers to make. The sperm donor had not yet consented to on-donation of embryos created from his gametes but the egg donor has not consented to on-donation so the embryos will be for the intending mother's use only.
- The Committee noted some slight inconsistencies in the documentation which it did not consider to be a barrier to approving this application. The Committee noted that the timing of counselling sessions can sometimes play a part in what information is relayed when, which may account for some of the inconsistencies in this case.

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.

7. Application E24/127 for surrogacy involving an assisted reproductive procedure with egg donation

Annabel Ahuriri-Driscoll 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 (IP1 and IP2) are a male couple requiring egg donation and surrogacy to begin their family. The surrogate is a friend of the intending parents and offered to be their surrogate to help them have a family. The egg donor is IP2's sister.
- Both intending parents are fit and healthy, with their medical report noting a couple of health and mental health conditions which are well managed.
- The surrogate and her partner have children and consider their family complete. The surrogate experienced uncomplicated pregnancies and births. She has one kidney which functions well with no need for medication. While this places her at higher risk of pre-eclampsia than the general population, there is a small absolute risk, and her renal physician is comfortable with her acting as a surrogate. The surrogate has been informed of this as well as the risks

associated with carrying a surrogate pregnancy. To mitigate these risks, it has been recommended that she be referred for obstetric oversight and give birth in hospital.

- The egg donor and her partner have two children and consider their family complete. The donor is fit and healthy with no medical history to note. The egg donor and her partner are currently living overseas and plan to return to New Zealand to undergo the egg donation cycle.
- The intending parents will use the donor eggs and IP1's sperm to create embryos, which will allow both intending parents to have a genetic connection to a resulting child.
- Any resulting child would grow up as a cousin to the egg donor's children and the parties plan to be open with the child about the donation to support their understanding of their identity. The intending parents and surrogate parents have also discussed their ongoing relationship and transparency with any resulting child about the surrogacy arrangement. There was no evidence of coercion in this arrangement and the Committee acknowledged the positive involvement of the parties in the letters of support from the intending parents, egg donor and surrogate with the language used in the letters.
- The egg donor has been informed that she can withdraw her consent to donate up until embryos are created. All parties have been informed that any decision to terminate a pregnancy would legally lie with the surrogate.
- The intending parents and surrogate parents have received independent legal advice, including advice regarding wills. The egg donor and her partner have agreed to be elected testamentary guardians for a resulting child.
- The Committee agreed that given the surrogate's heightened risk of pre-eclampsia, they would endorse the recommendation that she delivers in hospital where support could be provided to protect her wellbeing and that of the potential child.

Decision
The Committee agreed to **approve** this application subject to the surrogate agreeing, when pregnant, to be referred for obstetric care and delivery in hospital.

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

8. Request E24/128 non-binding ethical advice on transfer of affected embryos

Dr Emily Liu opened the discussion for this request.

Issues discussed included:

- A fertility treatment provider has written to ECART to seek an ethical opinion/advice on transfer of embryos known to be affected by an autosomal dominant condition which means that a potential child has a 50% chance of being affected by the condition.

- The symptoms of the condition range in severity, from very mild and benign to very severe. It is not possible to predict what the symptoms will be in a potential child even when a parent has a mild form.
- The intending parents have elected to terminate a pregnancy in the past because they did not wish to have an affected child. Subsequently, the couple had IVF treatment to create embryos that then had PGT testing for the condition to eliminate it in potential offspring. They went on to have an unaffected embryo transfer and a child was born. The couple then through spontaneous conception had another child, who has a mild form of the condition. They wish to have another child and the remaining embryos from their IVF treatment are all known to be affected with the condition. The intending mother is now at an advanced maternal age, and the request states the result from further IVF treatment at her age to create the embryos might not give an optimal result.
- The Committee has been asked for its view on transfer of the affected embryos knowing that a child will be born with the condition.
- Included with the request are two letters from specialists. One comments on two embryos that were unaffected but were aneuploid embryos not suitable for transfer and, the other from a clinical geneticist and paediatrician of the family, signals his support for transfer of the affected embryos. He states that the couple are well-informed about the condition and, that it is a condition that can be managed.
- The Committee agreed that within the current regulatory framework this matter is one open to ECART to give non-binding ethical advice on. That is because PGD testing and use in this situation, fall withing the definition of an established procedure within the current regulatory framework, and there are no ACART guidelines that cover transfer of affected embryos.
- ECART's authority to give non-binding ethical advice (rather than a decision) on established procedures comes from section 28(e) of the HART Act. The function was assigned to ECART by a previous Minister of Health in 2011. The Committee also noted that in the UK, a comparable jurisdiction, that law is also permissive of ethical advice being sought from an ethics committee when embryos carry a genetic mutation.
- What is important for ECART in giving any non-binding ethical advice, is to be able to clearly articulate its process of reasoning of the ethical considerations and risks and, it was agreed that in order to help it demonstrate an ethical analysis in this case, the Committee needs more information about the scope and effect of the condition to help it weigh and balance what the known risk/s to a potential child might be.
- As part of any ethical analysis, ECART could also draw on previous decisions that involved transfer of embryos with known conditions and note what was of importance to the committee in making those decisions and why.

Decision

- The Committee agreed to **defer** giving an ethical opinion to ask for further information from a clinical geneticist that details what the risks of mild to severe expressions of this condition are/sets out the implications of the mutation and spectrum of phenotypes for this specific mutation.

Actions

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

9. Application E24/129 for the creation of embryos from donated eggs and donated sperm

Pete Le Cren 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 have a long history of failure to conceive and unsuccessful IVF treatment. As the intending mother has low ovarian reserve and the intending father has azoospermia, the donation of eggs and sperm is considered the best option for the couple to begin their family. Both the egg and sperm donors are clinic donors unknown to the couple.
- The intending mother has been informed of the risks of carrying a pregnancy at an advanced maternal age and obstetric care has been recommended to mitigate these risks.
- The egg donor and her partner have children and consider their family complete. The donor had a hysterectomy following complications after a delivery but has been informed that this does not place her at a higher risk of complications than anyone else undertaking an IVF cycle. She has a family history of a neurodegenerative condition, however, the risk of a potential child developing this would be low. The egg donor has some recessive gene mutations which are not shared by the sperm donor and this information has been shared with the intending parents.
- The sperm donor is healthy and has no significant medical history to note. He has not met, nor seen the profile of the intending parents but has been informed that his profile was chosen by a couple.
- The family of the intending parents live overseas. Their families know that they have been receiving IVF treatment, however, the intending mother's sister is the only one who has been informed about the planned donation at this point.
- The intending parents plan to raise any resulting child in the New Zealand culture while educating them to understand their religion. The sperm donor shares the same ethnicity as the intending parents and the couple feel that this shared origin may help the child to feel a sense of belonging in community gatherings and trips to their home country.
- The intending parents were initially reluctant to disclose donor conception to any resulting child as the help of a donor is not often disclosed in their culture, but after ongoing discussion in counselling sessions they now feel it is their duty to help any child understand their biological origins. The intending parents do not anticipate initiating contact between a resulting child and the donors but would allow this decision to be made by the child in the future.
- The egg donor is open to being contacted by any resulting child in the future. She has shared her plans to donate with her parents and family members. The sperm donor has shared his decision to be a clinic donor with his friends but not with his family, who hold different values around this than he does. He would be open to sharing his culture and history with a resulting child in the future.

- All parties have been informed that the egg and sperm donors can withdraw or change their consent up until embryos have been formed.
- ECART acknowledged the potential stigma around donor conception culturally but wished to emphasise the importance of early disclosure to the child about their donor identity and noted that this has been found to be important for the identity and wellbeing of donor conceived children. The Committee noted that transparency would be particularly important for any child born from this arrangement given that their European heritage from the egg donor may mean they have a different appearance to the intending parents.

Decision
The Committee agreed to **approve** this application and encourage early disclosure with any resulting child about their donor conception.

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

10. Application E24/130 for the donation of eggs between family members

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:

- In this intended arrangement the egg donor is the sister-in-law of both intending parents. Both couples live together and effectively function as one family in which there are two couples and three children (one child is the intending parents' child and the other two children are the donor couples' children), in the household. The intending parents and the donor parents emigrated to New Zealand together some years ago and lived through that process together.
- The intending parents' child was conceived spontaneously and has a neurodevelopmental condition which has been a big adjustment for the intending parents and the extended family as the child is the first child in the family to have such a condition. The intending parents are seeking gamete donation as they want to reduce the chance of a future child having the condition.
- Three of the four adults in the household are in paid employment. The egg donor is not in paid employment, and she currently cares for the children full time, including the intending parents' child. She will be primary carer of all of the family's children.
- The Committee discussed whether it could be satisfied on the basis of the information before it that the intended gamete donation would meet the ACART guideline requirement that it offers the 'best or only' opportunity to have a child.
- The Committee acknowledged information stated in the reports from the intending parents' perspective that talked to the difficulty of raising a child with the condition and that they would want to minimise the chances of having another child with the condition through use of donated gametes. The Committee noted that information it has about the chance of a child having the

condition suggests that while there is a significant risk (1 in 5 chance) there is also a high chance that the child will not have the condition and, because the intending parents could conceive naturally, the intended donation may not meet the 'best or only' opportunity for them to have a child.

- The Committee noted that there are some questions around the genetics of the condition the intending parents' existing child has. It is a complex condition and while it is highly genetic, the process for that is not well-understood. Until recently the thinking was that the maternal genetics might be a strong factor in determining whether a child has the condition, but this thinking has shifted in past couple of years with new evidence to suggest that paternal genetics are the strong factor.
- While the reports note that the intended donation makes sense to the intending parents, the reports do not explicitly note that donation is the clinically advisable plan. The Committee noted that that length of time it took the couple to conceive could be related to either male or female factors but there seems to be an assumption that the female factor is the reason and, there do not appear to have been investigations of egg or sperm quality. The reports note it is immaterial about whose eggs will be used in treatment, but they do not comment on whether the same applies for the male gametes.

Decision
The Committee agreed to **decline** this application as it was not satisfied that the reason for the intended donation meets the 'best or only' threshold clinically.

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

11. Application E24/131 for surrogacy involving an assisted reproductive procedure

Simon McDowell 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 a hysterectomy and surrogacy is the only option for the intending parents to have a biologically related child. The intending mother has children from a previous relationship and the intending father has no children.
- The surrogate met the intending mother through a family member and wished to help after hearing the intending parent's situation. The surrogate and intending mother have since become friends and catch up regularly.
- The intending parents are fit and healthy with no apparent genetic disorders. They have created embryos with their gametes.
- The surrogate and her partner have children from previous relationships. The surrogate's previous pregnancies and deliveries were relatively uncomplicated, and she has been informed of the increased risks associated with carrying a surrogate pregnancy.

- The children and wider family of the intending parents are supportive of the intended arrangement. The intending mother's children were involved in a counselling session and had the opportunity to ask questions to better understand the process.
- The intending parents plan to tell any resulting child of the surrogate's role early in the child's life and to have an ongoing relationship with the surrogate, with her having an aunty role with the child.
- The surrogate has Māori heritage and in counselling shared that she was disconnected from this ancestry but that she wished to have the placenta back after birth to bury it. This has been shared with the intending parents and they are happy with this arrangement.
- Both parties have been informed that any decisions regarding termination would legally lie with the surrogate. Both parties have received independent legal advice and the intending parents have received an adoption order in principle from Oranga Tamariki.
- The Committee noted the importance of the intending parents appointing testamentary guardians in the event that they could not care for a resulting child and noted the surrogate's wish for them to do this also.

Decision
The Committee agreed to **approve** this application and would encourage the intending parents to appoint testamentary guardians in the event that they could not care for a child born from this arrangement.

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

12. Application E24/132 for surrogacy involving an assisted reproductive procedure

Richard Ngatai 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 have had extensive fertility treatment that has included a number of transfers without a successful pregnancy carried to term/recurrent implantation failure. Medical advice is that a surrogacy arrangement would give them the best chance of having a biological child and, the couple are continuing on with IVF treatment to see whether they can create euploid embryos for transfer to the surrogate in this intended surrogacy arrangement. If treatment is approved and the arrangement is successful, a child born would be the full biological child of the intending parents.
- The surrogate couple have children of their own and consider their family to be complete. The important considerations for the surrogate in carrying a surrogate pregnancy have been discussed with her and this discussion has been set out in the medical report along with her own pregnancy and birthing

history. The birth of her first child was complicated but subsequent pregnancies were not and there are no concerns medically that the intended arrangement would pose great risk to her or the potential child and, delivery of the intending parents' child in this intended arrangement is a planned c-section as requested by the surrogate.

- The surrogate takes medication for a condition that is deemed not to pose a risk in pregnancy and a specialist report included with this application is supportive of her acting as a surrogate – noting the view that she has the resources and support to navigate the intended arrangement. The report recommends the surrogate continue to receive follow up during and early post-pregnancy.
- The parties in the intended arrangement are friends of some years having been work colleagues in a close-knit community. The intending parents know the surrogate couple's children and they have prepared a support plan for the surrogate which includes helping with meal preparation, household tasks, and childcare duties should that be needed if treatment is successful, and the surrogate needs to attend appointments.
- The reports note that no coercion for surrogate is apparent, she has made her offer freely with her primary motivation to help her close friends start their family, knowing of their fertility journey.
- Pregnancy and birth plans have been discussed in counselling sessions. The couples share similar views including on termination and all know that the decisions about the pregnancy and birth are legally the surrogates to make.
- The intending parents anticipate close future contact with the surrogate couple and family, and the surrogate parents will have a social aunty and uncle role with the child in the way that they do for the surrogate couple's children. The intending parents have declared intentions to be open with the potential child and say they are committed to this and have a plan in place for the child to know from birth to normalise the role the surrogate played as soon as possible. The surrogate has started talking with her eldest child about the intended arrangement. It is anticipated that the children in both families will have regular contact.
- Both parties have received independent legal advice. The parties have been advised about the lack of enforceability of the surrogacy arrangement. The intending parents intend to adopt any child born of this arrangement and they have been advised of the legal requirements of the HART Act and have made plans for an adoption order and have received approval of an adoption order in principle from Oranga Tamariki. Both parties have been advised of the need to have updated wills and testamentary guardianship arrangements in place.

Decision
The Committee agreed to **approve** this application and to note it supports the recommendation for the surrogate to have check ins with counselling services during the pregnancy and early post-pregnancy.

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

13. Application E24/133 for surrogacy involving an assisted reproductive procedure

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.

Issues discussed included:

- The intending parents have had a difficult fertility journey with multiple miscarriages. The intending father has a low sperm count and received treatment in the past to have a child with a previous partner. Surrogacy is now the best option, both physically and psychologically, for the intending parents to have a child.
- The intending mother has no children, and the intending father has a child from a previous relationship. The intending parents are in good health with no genetic conditions to note. The intending mother experienced significant trauma from multiple pregnancy losses and emergency treatments and an independent psychological assessment supported the need for surrogacy to prevent further psychological harm to her.
- The surrogate is the sister-in-law of the intending parents, and the couples see each other regularly. The surrogate had previous uncomplicated pregnancies and deliveries and has been informed of the risks associated with carrying a surrogate pregnancy.
- The parties have informed some of their family members and friends about the intended arrangement and this has been met with support. The intending parents and their wider family live close to the surrogate parents and would be able to provide support to them during a pregnancy.
- All parties are committed to supporting their existing children and any resulting child's understanding of the surrogacy arrangement by informing them early on and, given that the parties are family, they anticipate continuing to have a close relationship in the future.
- Both parties have received independent legal advice and Oranga Tamariki has approved an adoption order in principle. The parties have also been informed that any decision around termination of a pregnancy would legally lie with the surrogate.
- The Committee noted that they didn't see evidence of discussions about testamentary guardianship in the legal reports for the intending parents or surrogate parents and would encourage both parties to appoint testamentary guardians in the even that they were unable to care for a child born.

Decision

The Committee agreed to **approve** this application and would encourage both parties to have discussions about testamentary guardianship if they have not done so already.

Actions

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

14. Application E24/134 for surrogacy involving an assisted reproductive procedure with egg donation

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.

Dr Simon McDowell declared a conflict of interest as he is the physician for the surrogate and the Committee agreed that he would not take part in the decision-making for this application.

Issues discussed included:

- The intending parents are a male couple who require an egg donor and surrogate and the intended surrogacy arrangement with egg donation gives them the best opportunity to have a biologically related child. In this intended arrangement the intending parents would wish to use IP2's gametes and IP1's sister's eggs to create embryos for transfer to the surrogate. The surrogate is a life-long extended family member of IP1. Both the egg donor and the surrogate consider their families to be complete.
- There is no undue influence on any of the parties that is apparent to counsellors and the parties have entered into the intended arrangement willingly and in an informed and consenting way.
- The existing close family ties and the parties' intentions to be open with any child born of this arrangement protect the well-being of all and including the best interests of the existing children who are young and will be told at an age-appropriate time and who will continue to have social relationships with the intending parents and their child. Plans are in place to maintain family connections offshore with family who are living offshore.
- The medical report for the intending parents' states that they are both in excellent health and does not note any medical reason or risk to IP2 that would be a barrier to use of his gametes to create embryos. The medical report for the surrogate raises no medical concerns about her acting as a surrogate and notes the risks to her have been explained. She has had previous c-section deliveries and a c-section delivery is recommended again and she has indicated that she would consent to referral to her local hospital clinic, once pregnant. The intending parents have been advised of this.
- Treatment, pregnancy, and birth plans have been discussed in counselling sessions. The egg donor lives offshore and is aware that she can seek further counselling post treatment in her home country should she need.
- The intending parents and the surrogate parents have received independent legal advice about the legal framework and process involved in surrogacy arrangements. Both parties have discussed the need to update wills and have testamentary guardians appointed in the context of these legal advice discussions. The intending parents have engaged with Oranga Tamariki and have received approval for an adoption order in principle. There is an agreed practical support plan for the surrogate within the legal framework.

Decision

The Committee agreed to **approve** this application subject to the surrogate agreeing, when pregnant, to be referred for specialist care through her local hospital clinic.

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

15. Application E24/135 for surrogacy involving an assisted reproductive procedure with egg donation

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.

Issues discussed included:

- The intending parents (IP1 and IP2) are a same sex male couple requiring egg donation and surrogacy to begin their family. Embryos were created in a previous application; however, the previous surrogate withdrew from the application and the intending parents are now applying with a new surrogate. The egg donor is a friend of the intending parents, and the surrogate was met through a mutual friend.
- IP1 is healthy with no notable medical conditions. IP2 has a chronic condition which is well managed with medication. IP2's family history includes a medical condition on the paternal side but no other significant medical issues.
- The egg donor has donated eggs already and was not found to be a carrier of any genetic conditions.
- The surrogate is a single mother who experienced uncomplicated pregnancies and deliveries. The surrogate has been informed of the risks associated with carrying a surrogate pregnancy at an advanced maternal age. The Committee noted that while she has mitigated the risk of pre-eclampsia by significantly reducing her BMI, given the other risk factors of advanced maternal age, length of time since her previous pregnancies, and surrogacy, they would endorse the recommendation for the surrogate to receive obstetric care during any pregnancy.
- During a pregnancy, the surrogate's main functional support would be her oldest child and her family. The intending parents also plan to provide support. Given that some of the burden would fall on the oldest child to provide support, the Committee agreed that counselling should be offered to the child to have the opportunity to discuss the implications of this.
- The intending parents are not from New Zealand and intend to raise a resulting child with an understanding of each of their cultures, as well as of the egg donor's culture. All parties intend to be open with the child about their genetic heritage and conception story to support the child's understanding of their identity.
- Both the intending parents and surrogate have received independent legal advice including advice regarding wills and testamentary guardianship and the intending parents have received an adoption order in principle from Oranga Tamariki. Both parties have been informed that any decision regarding termination would legally lie with the surrogate.

Decision
The Committee agreed that it would **approve** this application subject to the condition that the surrogate agrees, when pregnant, to obstetric care. The Committee would also encourage the surrogate's oldest child to be provided with the option of counselling given that they would be providing support for her during a pregnancy.

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

16. Application E24/136 for embryo donation for reproductive purposes
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:

- The embryo donors have chosen to donate their remaining embryo created for use in their own IVF treatment to the intending parents who are their long-standing friends.
- The IPs have had a number of fertility treatments using their own gametes without success. There seems to be an issue with egg quality and reserve and the medical report for the intending parents notes that the egg donor waiting list has a very long wait time. They have been advised that embryo donation offers them the best opportunity to have a child.
- The donor couple and their family's medical history is set out in their medical report and the intending parents have been advised of the history that is relevant to the health of their potential child. The intending parents have declared they would care for and raise any child born of this donation.
- The intending parents are Chinese and have lived in New Zealand for some years and have developed a strong network of friends and have a supportive social environment. They also describe continued ties with their families offshore who are supportive of the intended arrangement.
- The intending parents know that the resulting child won't share their physical characteristics, the implications of which were discussed in counselling. The rights of the child to know their biological parents were discussed and the intending parents have declared intentions to be open with any child born of this arrangement and to raise the child in a way that meets their cultural needs.
- The rights of each of the parties in relation to transfer of embryos, pregnancy and parenting have been discussed during counselling sessions. The requirements of the HART Act for the child to access information about the donors when the child turns 18 has also been discussed with both parties.
- The parties have an established friendship and anticipate that this will be ongoing and the interests of all, including the existing and potential children, will be safeguarded in the context of their existing relationship. Both parties have expressed a desire for their children to know each other.

Decision

The Committee decided 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.

17. Application E24/076 for surrogacy involving an assisted reproductive procedure

Lana Stockman 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 application in April 2024 and noted that the medical report did not provide enough information to determine whether the intended arrangement met the threshold of the 'best or only' option for the intending parents to have a child. The Committee deferred the application to request a medical opinion from an independent fertility specialist to help the Committee determine whether surrogacy is the best or only option. The Committee also requested that the intending parents appoint testamentary guardians in the event that they themselves could not care for a child born from the arrangement.
- Since the original consideration, an additional specialist report has been provided which explains the intending parent's medical history and that future implantation would likely be unsuccessful. While there was no identified cause for the recurrent implantation failure, the medical report supported that surrogacy would be the best option for the intending parents to begin their family. The Committee agreed that this report provided the assurance that surrogacy is the best or only option in this arrangement.
- The Committee also noted the statement from the intending parents which appointed the surrogate parents as testamentary guardians and that the surrogate parents had agreed to this. The Committee was satisfied that the intending parents had acknowledged the need for testamentary guardians.

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.

18. Consideration of extended storage applications

Meeting close
Confirmation of next meeting on August 16th 2024.

Richard Ngatai led the closing Karakia.

Minutes of the Ethics Committee on Assisted Reproductive Technology
17 May 2024

1. Reconsideration of application E22/065 for post-humous use of sperm

The Committee reconsidered this application in relation to the HART Act 2004 principles and the *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man (2000).* ECART also took into account the summary of submissions on ACART's Consultation on *Proposed Guidelines for the Posthumous Use of Gametes (2019; 2021).* (While the proposed Guidelines are yet to be published and are not yet in force, the analysis of submissions were published in 2019 and 2021 respectively and provide insight into views of the public which is a relevant consideration under s 4(g) of the Act.)

Issues discussed included:

- This application is for the posthumous use of sperm by the deceased man's partner. In reconsidering of this application, ECART noted the information included in the original application in 2022; specifically the letter from the fertility clinic counsellor, medical specialist, and letters of support. The Committee also noted the additional information provided for the purposes of the reconsideration, including the new statement from the applicant, a statement from the deceased's parents, affidavits from the applicant's mother and from the deceased's colleagues and friends, as well as the original consent form for the storage of sperm and letters from the clinic to the deceased.
- The Chair outlined the legal framework relevant to the decision, specifically the guiding principles in section 4 of the HART Act 2004, and the HART Order 2005, which notes 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 Chair also outlined the ethical considerations in the *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man (2000),* noting that the Guidelines provide ECART with discretion to consider an application where: 'consent has not and cannot be obtained, or when there is a request for a variation of these requirements'. It was noted that in the current situation, ECART had discretion to consider the application on the basis that a variation to these requirements is being requested.
- The Committee discussed the appropriate weight that should be placed on the issue of consent to posthumous use, and the standard of consent required in the context of other relevant considerations. The Committee discussed the distinction between actual consent where there is evidence that consent was actually provided prior to death, and inferred consent where acts or conduct are relied upon to infer that a person would consent if given the opportunity. The Committee noted the distinction between consenting to parenthood when alive, versus consenting to parenthood after death.

- ECART discussed the relevance of the consent form originally signed by the deceased when storing sperm for the purpose of fertility preservation, in which he indicated a preference for disposal of sperm in the event of his death. The Committee decided that given the passage of time since it was completed and the deceased's altered circumstances it could not be determinative in the circumstances.
- The members of the committee identified questions for the applicant relating to: matters raised in the original counselling report; the distinction between the deceased wanting a child whilst alive and consenting to having a child after death; the nature of her relationship with the deceased; and the interests of any child born.
  The applicant elected to present a statement to the committee in person, and then answered questions from the Committee. This provided an insight into her deceased partner's character; their relationship and goals; their conversations regarding his occupation and associated risks; their discussion of the risk of potential death and its implications for their reproductive plans. Further context was provided by the applicant regarding the circumstances and significance of the discussion between the applicant and deceased man shortly before his death about the possibility of her using his sperm in the event he died.
- ECART discussed whether it was satisfied that the deceased gave voluntary and express verbal consent to the posthumous use of his stored sperm by his partner. The Committee relied upon the applicant's account of the events preceding the discussion between her and the deceased, the nature of the discussion involving posthumous use of the deceased's stored sperm; as well as the supporting affidavit evidence provided relating to that conversation. The Committee took into account the deceased's familiarity with fertility treatment (both as a result of storing his sperm and his involvement in discussions with his partner) and his knowledge of the applicant's social circumstances and her preparedness to be a single parent if necessary.

- Based on the applicant's written and oral account and the affidavit from the deceased's mother, ECART is satisfied that the deceased gave verbal consent for the use of his sperm by the applicant in the event of this his death which was voluntary, sufficiently informed, and close enough to the time of his death to reflect his final wishes.
- The Committee discussed the implications for a child born as a result of posthumous conception. It noted the reference made by the applicant to children conceived as a result of donor conception raised by single parents. The Committee noted that donor conception is different and the implications for a child born as a result of posthumous conception may be experienced in different ways by a child. On one hand a child may feel left out of, and subject to a decision made by adults; on the other that with posthumous conception there will be no issues of identity, and in this particular case any child born would be brought into a family where the intending parent is connected to the deceased's family. The Committee also noted that the applicant made it clear in the discussion that she wants a 'choice' to have a child; that she would

need to be clear herself that having a child is the right decision for her and would seek further counselling prior to committing to attempting to conceive.

- On balance, the Committee considered the interests of the child were protected in the context of this particular application. The applicant shared that the child would have access to information about their father as well as being brought up in a community of his family and friends. The Committee was satisfied that the applicant had received counselling, and noted her intention to obtain further counselling should she commence treatment.

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.