

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

16 August 2024

Held online on 16 August 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
Mike Legge	Member
Peter Le Cren	Member
Richard Ngatai	Member
Simon McDowell	Member

Karen Reader ACART member in attendance

ECART Secretariat

Apologies
Angela Ballantyne

1. Welcome

The Chair opened the meeting and welcomed all in attendance.

2. Karakia

Mania Maniapoto-Ngaia led the Karakia.

3. Conflicts of Interest

ARP 20899 - Dr Emily Liu declared a conflict of interest and did not take part in the decision making for this application.

4. Confirmation of minutes from previous meetings

The minutes from the 20th June 2024 meeting were confirmed.

5. Application ARP 20899 for surrogacy involving an assisted reproductive procedure

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 had a long history of unsuccessful IVF treatment with recurrent implantation failure and pregnancy loss and surrogacy is now considered the best option for the couple to begin their family.
- The intending parents had a previous surrogacy application approved by ECART, but this arrangement did not proceed. The surrogate in this new application is a long-term friend of the intending mother.
- The surrogate parents have children and consider their family complete. The surrogate had previous uncomplicated pregnancies and deliveries (one by elective caesarean). However, she has thin endometrium that is not currently suitable for embryo transfer.
- The surrogate has been informed of the risks of carrying a surrogate pregnancy and she will receive obstetric care during a pregnancy.
- The intending parents have shared their surrogacy plan with close friends and family who are supportive of the intended arrangement.
- The surrogate parents have good support around them to help during any pregnancy. The surrogate has informed her family of the intended arrangement, and this has been met with support. The surrogate partner will inform his family soon and anticipates they will be supportive of the arrangement. The children of the surrogates are too young to be informed of the arrangement yet, but the surrogate parents intend to support them to understand the arrangement.
- Both parties plan to be open and help any resulting child to understand their conception story and the role the surrogate played in their life and see this as something that would happen naturally given their ongoing friendship.
- The surrogate parents live overseas but will travel to New Zealand for treatment where the intending parents' embryos are stored. The intending parents will travel overseas where possible to attend appointments and scans. Any child from this arrangement will be born in the surrogate's home country.
- Both parties have been informed that any decisions regarding termination would legally lie with the surrogate. Both parties have received independent legal advice from lawyers in New Zealand and overseas. The intending parents have discussed guardianship with the surrogate parents, who have agreed to be named testamentary guardians for a resulting child.
- The intending parents have been informed of the options for how a resulting child could travel back to New Zealand with them after the birth and will consult their legal representatives to decide on their preferred arrangement for this.
- The intending parents have received approval for an adoption order in principle from Oranga Tamariki and have been informed that once the adoption order is granted, a New Zealand birth certificate can be issued with their names as the legal parents, but the original birth certificate will remain overseas that names the surrogate parents as the legal parents.

- The Committee discussed the suitability of the surrogate given that she has thin endometrium that is not currently suitable for supporting a successful embryo transfer. The Committee noted the plan in the medical report to reassess the endometrial thickness and ways to address this if there is ongoing concern. ECART was satisfied that the intending parents had been counselled about the low chance of success with thin endometrium and agreed that the transferring of embryos would be subject to clinical review to ensure that the surrogate's endometrial thickness is suitable.

Decision

The Committee agreed to **approve** this application subject to it being clinically confirmed that the surrogate's endometrium is suitable to do an embryo transfer.

Actions

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

6. Application ARP 20791 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 in this intended surrogacy arrangement with donated eggs are a male couple who need a surrogate and an egg donor to help them have a family. Their friend has offered to donate eggs and IP1's sister has offered to act as their surrogate. IP1 will donate sperm (genetic screening has shown nothing of note that might impact on the health of the potential child), and embryos will be created with their donor's eggs.
- The intending parents describe a strong support network of family and friends who live in close proximity to them and who are aware of the planned donation and surrogacy arrangements.
- There are no concerns medically about the surrogate carrying a pregnancy for the intending parents and a condition that she does have is well managed and not contraindicated for pregnancy. The reports note discussion around the surrogate's delivery history noting that given her own history that she understands the risks. Pregnancy and birth plans and post birth plans have been discussed and agreed between the parties and they are supportive of the needs of all parties including the surrogate's existing children.
- The egg donor is of Māori ethnicity. Her motivation for the donation was discussed in counselling sessions and, she has given thoughtful consideration to her decision to donate and has been well counselled on the implications of the intended arrangement and has received medical assessment and advice on the risks associated with egg collection.
- If the treatment is successful and a child is born, they will be raised by the intending parents who are both of European descent. The egg donor has been raised in Te Ao Māori. The intending parents realise the importance of the egg

donor sharing information with them and with the potential child about her whakapapa and, with her own child so there is connection. They have talked about carrying this openness throughout the child's life. All parties understand the status of surrogacy arrangements according to the current law and what that means for birth records and registered information.

- The egg donor has talked about counselling being culturally appropriate for her and allowed for discussion about the cultural implications of the donation and allowed the opportunity for whānau involvement.
- The surrogate has experienced some reactive anxiety in the past and a report from an independent specialist was provided with this application and indicated that the surrogate is currently well. The specialist has recommended monthly health check ins during pregnancy and early in the post-partum period.
- Both parties have sought independent legal advice. The intending parents intend to adopt any child born of this arrangement and they have been advised to update their wills to include provision for testamentary guardianship of the child. Oranga Tamariki have approved an adoption order in principle for the intending parents.

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 ARP 20858 for surrogacy involving an assisted reproductive procedure with egg donation

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:

- The intending parents (IP1 and IP2) are a male couple requiring egg donation and surrogacy to begin their family. The intending parents met the surrogate parents through an online platform and the egg donor is their friend.
- The intending parents are in good health. In the past, they have accessed mental health services briefly, but have not had ongoing mental or physical health difficulties.
- The surrogate parents have children and consider their family complete. The surrogate is in good health and had previous uncomplicated pregnancies and deliveries. She has been informed of the risks of carrying a surrogate pregnancy. The surrogate experienced post-partum depression after the birth of her first child due to situational factors at the time. A clinical psychologist report provided with this application supports her acting as a surrogate and, emphasised that she has a good understanding of her own wellbeing and how to access her support system. The psychologist report also identified that the surrogate may be at higher risk for distress from the process of relinquishing any resulting child, which was explored in counselling. The surrogate is

confident in her ability to seek support from those around her or from appropriate services if she feels distress at any stage of the surrogacy process.

- The egg donor offered to be the donor for her friends after speaking with her partner and children to ensure they were comfortable with her decision. She is in good health with no identified health issues in her immediate family that would significantly impact on a resulting child. The egg donor has been informed of the risks of egg collection and is aware that she can withdraw her consent to donate up until embryos are created.
- Embryos will be created from the egg donor's eggs and IP1's sperm to maintain his links to iwi and protect his whakapapa. The egg donor and IP1 share no carrier conditions.
- The intending parents and surrogate parents have built a relationship since connecting online and the intending parents have met the surrogate parents and their children in person. The surrogate parents have a good support network around them to help during a pregnancy.
- IP1 is Māori and IP2 is of NZ/European heritage. The intending parents have expressed their intention to raise the resulting child with a strong emphasis on Māori culture and Te Reo Māori.
- All parties are committed to being open and transparent with any resulting child about their origin story and to support them to understand this. All parties intend to stay in contact with one another and to communicate with each other as the situation unfolds about what level of contact feels appropriate.
- The intending parents are currently living overseas for work and are scheduled to return to New Zealand in a couple of years. They are open to returning earlier if needed or for a period before or after the birth. They have returned to New Zealand multiple times during the application process to attend medical and counselling appointments.
- All parties have been informed that any decision to terminate a pregnancy would legally lie with the surrogate. The intending parents have expressed that they would request the opportunity to try and reach a consensus around decisions to terminate a pregnancy.
- The intending parents and surrogate parents have received independent legal advice, including advice regarding wills, and close friends of the intending parents have agreed to be appointed testamentary guardians for a resulting child. The intending parents have also received an adoption order in principle from Oranga Tamariki.
- The Committee acknowledged the thoroughness of the surrogacy support plan and letter from the intending parents and noted the high quality of the application.

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.

8. Application ARP 20788 for surrogacy involving an assisted reproductive procedure

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 are a heterosexual couple who present with a long history of trying to conceive, including with the help of fertility treatment, without success. They have received medical advice that a surrogacy arrangement would give them the best or only option to start their family and, they have embryos created from their own gametes that they would like to be able to use in the intended surrogacy arrangement.
- Important medical considerations for the surrogate have been set out in the reports. Given her pregnancy and delivery history, she would prefer a c-section delivery. The surrogate disclosed an episode of depression post-partum that was considered to be situational. She was treated at the time and has not had any further episodes. An independent specialist report submitted with this application outlines the historical factors and notes she is stable, has emotional support available and is in a good place to be a surrogate.
- The surrogate parents have some insight into third party reproduction which the intending parents are aware of. Since meeting online, they have developed a relationship to the extent that they have met some extended family members and, they anticipate their relationship will continue long-term regardless of the outcome of this intended surrogacy arrangement.
- The parties have discussed pregnancy, birth and post-birth plans and are in agreement about the care the surrogate will receive during the pregnancy and delivery given her history and they are aligned in their thinking.
- The intending parents have shown insight in relation to the surrogate's previous preterm delivery experience and, an awareness that it could reoccur and its potential impact for the surrogate.
- The Committee discussed whether the medical report for the surrogate provided adequate information regarding her birth history and potential risks relating the proposed surrogacy. The medical report briefly notes the history of intrauterine growth restriction and pre-term delivery with respect to her prior birth, but did not provide further detail. The Committee noted the risk of this reoccurring in a surrogacy pregnancy. The Committee agreed there is not enough information in the medical report to assess those risks and to ensure that the intending parents are aware of those risks. The Committee agreed it would want to be reassured that the intending parents have been counselled about the risks.
- The reports note that the surrogate has a good support network. She has discussed the intended arrangement with her own children and has arranged for regular appointments with clinic counsellors when a pregnancy is established.
- The intending parents have received approval for an adoption order in principle from Oranga Tamariki. They have appointed testamentary guardians. Both parties have received independent legal advice, and the reports are

comprehensive and cover all requirements. The surrogate parents have also been informed about the need for them to update their wills and to have testamentary guardianship arrangements in place for their own children.

Decision

The Committee agreed to **defer** this application to request that the surrogate undergoes an independent obstetric review, in particular the Committee requests additional information regarding the IUGR and preterm delivery noted in relation to her prior birth experience, any potential risks in relation to the proposed surrogacy, and to request that this information is shared with the intending parents.

Actions

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

9. Application ARP 20790 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 parents have a long history of unsuccessful embryo transfers and multiple pregnancy losses with complications requiring treatment. Surrogacy has now been recommended as the best opportunity for the intending parents to have a child. The surrogate is the sister-in-law of the intending parents.
- The surrogate parents have children and consider their family complete. The surrogate had previous uncomplicated pregnancies and births. She has undergone obstetric specialist review and has been informed of the risks of carrying a surrogate pregnancy.
- Both parties have a close relationship with one another and intend for this to continue during and after this arrangement. Both parties intend to be open and honest with any resulting child about their origin story from birth. The surrogate parents have discussed the arrangement with their children in an age-appropriate way and both parties have informed their wider family.
- The surrogate parents will be social aunt and uncle to any resulting child and their children will be social cousins. They imagine that their active role in each other's lives will continue.
- Both parties have discussed termination of a pregnancy and intend to be open and supportive with their communication around this should they need to make this decision. Both parties have been informed that any decision around termination would legally be the surrogates to make.
- Both parties have received independent legal advice, including advice regarding wills and testamentary guardianship.
- The intending parents have received approval for an adoption order in principle from Oranga Tamariki.

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.

10. Application ARP 20844 for the creation of embryos from donated eggs and donated sperm

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 parent is a single woman with Turners Syndrome who has applied to ECART in the past to use donated gametes to create embryos for her use. ECART declined the application on the grounds that it was not medically safe for her to carry a pregnancy. This is her second application with further medical evidence provided that supports her carrying a pregnancy.
- Specialist reports submitted with this application note that while there are some increased risks of development of gestational diabetes, hypertension, and pre-eclampsia in pregnancy, that adequate screening before pregnancy mitigates those risks. Her specialist obstetrician is supportive of her carrying a pregnancy. Her cardiology assessments are current and do not note any concerns of pregnancy being contraindicated. The plan is for her to have obstetric care during a pregnancy.
- Specialist comment is that there is no structural abnormality of the aorta and the Committee noted that this is the important thing to note in a patient who has Turners Syndrome carrying a pregnancy.
- Her condition is one that carries a spectrum of risks, and she has had a thorough review from a highly experienced medical practitioner looking after women in this patient group. With this reassurance, the Committee agreed it was satisfied that pregnancy risks presented can be monitored and managed.
- The Committee discussed that that the reports set out that there is up to 35% risk of the intending parent developing hypertension in pregnancy, which means there is a high risk of premature birth. The risk of the baby being born small for gestational age was noted in the reports at 20%. While the reports are clear that the intending parent has taken on concerns about risks to her health, they did not so clearly document whether she had considered the risks to the potential child. It was noted that there was no discussion in the reports of a contingency plan given her circumstances, for care of the child in the event that anything happens to her, and it was queried whether she is taking on risks to herself without full consideration for the potential child. The Committee noted that the risks to the future child set out in the reports are risks that apply across many situations other than this one and, the intending parent has had thorough medical counselling with two obstetric physicians, which reassured the Committee that overall she has been extensively counselled.

- A personal egg donor (who is a long-standing and close friend), and a clinic sperm donor are the gamete donors in this application. The sperm donor is a donor conceived child himself and his parents disclosed this when he was young. He is motivated to pass on the gift he was given as a donor conceived person.
- The intending parent has declared intentions to tell a child their conception story and would contact the clinic if the child requests identifying information about their biological father, the sperm donor. Information about the egg donor will be shared in the context of their continued friendship and the egg donor's children will also be informed. The egg donor and her partner will be social aunty and uncle to a child born of this arrangement.
- Genetic screening has been done for both donors. Two mutations were identified for the egg donor and were matched with the sperm donor, and they do not carry the same mutations. There are no other conditions identified that might be passed on to a child that would impact on the child's wellbeing. The egg donor has had a heart surgery procedure for a condition and medical advice is that the condition is not heritable.
- The donors have been advised that they can withdraw or modify their consent up to the point that the embryos are created and, that if a pregnancy is established the intending parent will have legal rights and responsibilities about the pregnancy and birth and parenting a child born of the arrangement.

Decision

After considering the comprehensive specialist medical reports, and evidence that the intending parent has been extensively counselled regarding the potential risks of pregnancy, the Committee agreed to **approve** this application. In the interests of supporting the welfare of any child born of this donation, the Committee would also encourage the intending parent to consider appointing a testamentary guardian in the event that she is unable to care for the child in the future.

Actions

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

11. Application ARP 20862 for the creation of embryos from donated eggs and donated sperm

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 intending parent requires donor eggs and donor sperm to begin her family due to having low ovarian reserve and being a single person. The egg and sperm donors are clinic donors, and the intending parent has met the donors in person facilitated by the clinic.
- The intending parent is in good health. She has been informed of the risks associated with carrying a surrogate pregnancy at an advanced maternal age and obstetric care has been recommended to mitigate these risks. The

intending parent experienced an episode of depression in the past and is on medication to manage this. She is also open to counselling on an ongoing basis if needed.

- The egg donor and her partner have children and consider their family complete. The egg donor is in good health and has been informed of the risks associated with egg collection. She has donated to another family requiring donor eggs and sperm in the past.
- The sperm donor has no children of his own but has donated to other families and is motivated through wanting to help people and to continue his family genetics. He has shared this information with the intending parent and has been informed that this is the maximum number of families that he will be able to donate to.
- Both donors have recessive gene mutations but have no matching gene mutations meaning the risk to a child of inheriting a serious genetic disease is low. The intending parent has been informed of this.
- The sperm donor has shared his plans for this donation with his friends. He is open to future contact with the intending parent and any resulting child from the arrangement.
- Both donors have been informed that the intending parent plans to create embryos with donor eggs and donor sperm, and that they can vary or withdraw their consent up until the point where embryos are created.
- The intending parent has informed her family and friends of the planned arrangement, and this has been met with support. She has also been informed of an online support group for people choosing to be single mothers.
- The intending parent plans to disclose any resulting child's origin story as soon as practicable. The intending parent is willing to support any future contact with the egg or sperm donor with a resulting child if the child requests this, as well as with any genetic half siblings the child may have.
- The Committee noted because the intending parent is receiving a double gamete donation and will be a single parent, it would encourage her to consider appointing testamentary guardians in the event that she could not care for a child born from this arrangement.

Decision

The Committee agreed to **approve** this application and supported the recommendation of specialist obstetric care for the intending parent. ECART would also encourage the intending parent to consider appointing testamentary guardians in the event that she 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 ARP 20859 for the creation of embryos from donated eggs and donated sperm

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:

- The intending parent is a single person requiring donor sperm to begin her family. She also requires donor eggs due to low ovarian reserve and advanced maternal age. The egg and sperm donors are clinic donors.
- The intending parent had previous unsuccessful fertility treatment in attempts to have a child using her own gametes before shifting to using donor eggs based on specialist recommendation. The medical report noted that she will require early referral to a preterm birth clinic for monitoring during a pregnancy due to an increased risk of having a premature birth as the result of a previous procedure. She has been informed of this as well as of the risks associated with carrying a pregnancy at an advanced maternal age and will also receive obstetric care throughout the pregnancy to mitigate risks to her and any resulting child.
- The egg donor has no children and does not intend to have them in the future. She had genetic carrier screening performed and no gene mutations were detected. The egg donor has been informed of the risks associated with egg collection and is familiar with the process having donated eggs twice before when she was overseas.
- The sperm donor and his partner have children and consider their family complete. He has been found to be a carrier of two recessive conditions which are not shared by the egg donor meaning any resulting child would not be at risk of inheriting these conditions.
- The sperm donor has informed his parents about the intended arrangement and will inform his children when they are older. He is open to being contacted by any resulting child either when they receive his identifying information when they are 18 years old or if there is an earlier request for contact that both parties agree to.
- The intending parent has the support of her family and friends in her decision to pursue this arrangement. She intends to be open and transparent with any resulting child about their origin story.
- The intending parent met the egg donor at the joint counselling session. The egg donor shared that she would be willing to be available for future contact with a child to answer any questions they have.
- The Committee noted because the intending parent is receiving a double gamete donation and will be a single parent, it would encourage her to consider appointing testamentary guardians in the event she could not care for a child born from this arrangement.

Decision

The Committee agreed to **approve** this application and would encourage the intending parent to consider appointing testamentary guardians in the event that she 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.

13. Application ARP 20864 for the creation of embryos from donated eggs and donated sperm

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 in this application is a single person who is seeking donated eggs and donated sperm for the creation of embryos as previous IVF treatment with her own eggs, and also a family member's eggs, and donated sperm was unsuccessful. Both donors in this application are clinic donors who were not known to her before the intended donation. They have since met for joint counselling sessions.
- The intending mother has been medically counselled about the risks of carrying a child at an advanced maternal age. Both donors have received genetic screening and there are no conditions identified that might be passed on to a child that would impact on the child's wellbeing.
- Implications counselling has covered parenting a child who is not genetically related; the intending parent has relinquished having a biological link with a child and is hopeful that donated gametes will help her start her family. She has shared information about the intended donation with key family and friends and they are supportive of her and her decision to continue with treatment.
- Rights and responsibilities have been set out and discussed in counselling sessions in relation to use of gametes, embryos and decision making about them. The intending parent has been advised of options for donor linking with the clinic and through the national HART donor register. The donors have been counselled about their rights prior to and after the creation of embryos for the intending parent's use. They know that when the embryos are transferred to the intending parent that any decisions about a pregnancy are hers to make.
- All parties have declared that they value openness, and the intending parent has declared intentions to be transparent with any child born of the donation about their genetic origins and their connection to both donors. She has said that she would support future contact between a child and their donors, and the donors have declared they are open to being contacted in future.
- A child born of this donation will have Māori ethnicity and the Committee discussed whether it considered that based on the information before it, that counselling had covered the implications of this. The Committee noted that the donor's ancestry was described in the counselling report, and talked about as having a distance, which might have had a bearing on the extent to which it was discussed in counselling sessions. The Committee noted its preference to consider a child's relationships to their whakapapa as separate from the donor so that it is not restricted or limited by a donor's relationship to their own whakapapa. The Committee agreed that it would approve this application and encourage the intending parent to consider how she would support a child with Māori ancestry.
- In the interests of supporting the welfare of any child born of this donation, the Committee would also encourage the intending parent to consider appointing a

testamentary guardian in the event that she is unable to care for the child in the future.

Decision

The Committee agreed to **approve** this application. In the interests of supporting the welfare of any child born of this donation, the Committee would also encourage the intending parent to consider appointing a testamentary guardian in the event that she is unable to care for the child in the future.

Actions

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

14. Application ARP 20813 for embryo donation for reproductive purposes

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 a considerable family building experience and, when IVF treatment using their own gametes was unsuccessful, they looked at other options for starting a family. They have a young child who they adopted into their family when they were a baby and they have declared that they have always wanted to parent more than one child.
- The intended embryo donation is made in the context of the friendship the two couples share. The donor couple live offshore in the country where they are citizens. The embryos the donor couple wish to donate were created from their own gametes for their own use in IVF treatment. They have children born from the embryos and they consider their own family to be complete. If ECART approves this application, the remaining embryos will be exported to New Zealand for the intending parents' use in their fertility treatment.
- The intending parents see the intended arrangement as the best opportunity for them to complete their family. They see equity in relationships for their child and potential siblings being held through them all not having a genetic link to the intending parents.
- The genetic and relationship considerations, given there will be full siblings in two families and that there will be a genealogical link between these families, have been discussed in counselling sessions. The donors have chosen to donate to friends who share similar values and beliefs with a desire to connect the families and protect the genealogical links for existing and resulting children.
- The intending parents are cognisant of the international aspect to this application as the donor couple live offshore. They have indicated that they are committed to recognising the potential child's cultural heritage via their link with the donor couple. They see similarity in the situation they share with their adopted child's biological family with whom they continue a relationship with for the child's well-being.

- Both couples have been advised about the legal aspects and requirements under the HART Act such as information sharing. The intending parents believe that the HART Act registry pathway, although available, will be unnecessary as they intend to maintain contact with the donor couple and their family. They say they are committed to transparency about the role the donors played for the sake of the children including the existing children in both families.
- The medical report for the intending parents is brief and apart from a note that sperm donation was considered and there was uncertainty of success, there was not full information about why the intended donation is considered to be the best or only opportunity for the intending parents to complete their family. With reliance on more detailed information provided in the counselling reports, the Committee agreed that while embryo donation is not the only opportunity, it was satisfied that in this case, it offers the intending parents their best opportunity to complete their family.
- Some of the donor woman's medical history is noted in the counselling reports and discusses a genetic condition with a note that it is not likely to be heritable and, has not been seen in the donor couple's children. The Committee noted that the genetic counselling had identified the condition as autosomal dominant that affects females more than males. Due to the fact that people with the condition have a higher risk than the general population, of developing renal cancer, the Committee were aware that the donor couple's children might be too young to have been tested yet may well be carrying the gene.
- The Committee noted that the medical report submitted with this application noted no hereditary conditions, even though the counselling report suggests the donor woman has had genetic testing and was found to have a backward F9 gene. The Committee noted that even if there is no familial history, this does not necessarily mean that she won't pass the gene on to the next generation.
- The Committee agreed that given the condition is an autosomal dominant condition, and that there may be a 50 percent chance that the remaining embryos carry the gene, it is seeking clarification and further information about the condition and its implications for the embryos, and reassurance that the intending parents are aware of any relevant new information, before making a decision.

Decision

The Committee agreed to **defer** this application to request clarification and further information about the egg donor's condition and its implications for the embryos and the potential child.

Actions

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

15.E24/128 request for non-binding ethical advice for transfer of embryos with a known genetic condition.

Jeanne Snelling opened the discussion for this request.

Issues discussed included:

- The Committee first considered this request at its June 2024 meeting and asked for more information around the type of risks, nature of the risks, the likelihood of the risks and the impact on a future child.
- The information was submitted after this meeting agenda close date and included a letter from a geneticist that stated it is not possible to predict the nature and the likelihood of an outcome. The Committee agreed that the letter from the geneticist needs further consideration with the expert view of its clinical members and, given the information was submitted to ECART after the agenda close date the Committee required more time to give some considered thought to its response.
- The Committee agreed that it could make use of an existing decision-making framework that sets out the steps and considerations clinics might take into account, and which identifies and acknowledges the complexity of decision making to assist clinics.

Actions

Secretariat to draft correspondence to the clinic advising that the Committee is working on providing a response that makes use of an existing framework and could be used as a guide for clinics to aid them in their decision making and, that the Committee will discuss this at their next meeting in October before providing a response.

16. Consideration of extended storage applications

Meeting close

Confirmation of next meeting on October 24th 2024.

Confirmation of ECART member in attendance at next ACART meeting on August 23rd 2024, Richard Ngatai.

Annabel Ahuriri-Driscoll led the closing Karakia.