

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

## 19 February 2024

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Held online on 19 February 2024

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### In Attendance

Jeanne Snelling	Chairperson
Analosa Veukiso-Ulugia	Member
Angela Ballantyne	Member
Annabel Ahuriri-Driscoll	Member
Lana Stockman	Member
Mania Maniapoto-Ngaia	Member
Mike Legge	Member
Peter Le Cren	Member
Richard Ngatai	Member
Jude Charlton	Member

Calum Barrett ACART member in attendance

ECART Secretariat

### Apologies

Emily Liu	Member
Simon McDowell	Member

### 1. Welcome

The Chair opened the meeting and welcomed all in attendance.

### 2. Karakia

Peter Le Cren led the Karakia.

### 3. Conflicts of Interest

No conflicts of interest were declared in this meeting.

### 4. Confirmation of minutes from previous meetings

The minutes from the 7<sup>th</sup> December 2023 meeting were confirmed.

### 5. Application E24/023 for donation of eggs between family members

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:**

- A chromosomal condition that resulted in the intending mother's ovaries being removed as a young person, means that gamete donation is needed. She does have a uterus and can carry a pregnancy. A within family egg donation is planned and the donated eggs will be used to create embryos in IVF treatment with the intending father's gametes.
- The medical reports for the parties do not raise any issues that might be relevant for the Committee to consider in relation to the intending mother's or the potential child's health and well-being. The difficult topic of termination of pregnancy was discussed in counselling sessions - all parties views align, and they know that the intending mother has the legal right to make any decisions about the pregnancy.
- The counselling reports for the parties also do not raise any ethical issues that the Committee might want to further explore in its discussion for this application.
- The intending mother has known from a young age that she would need donor eggs to have a family and has thought through the implications of not having a genetic link to a child. She and her partner have been fortunate to receive the offer of donation from their sister-in-law – the partner of the intended mother's brother. The counselling reports discuss the donor's motivations for this donation and reassure the committee that she has made her offer freely.
- Counselling sessions also canvas discussions around the rights and responsibilities of the parties in this intended arrangement, including storage and on-donation rights.
- The implications for the existing and potential children have been a particular focus and discussion on the ways to best support the donor's children and the potential child understand this journey, and the unique situation they will grow up in. They have declared intentions to be open about the role that the donor played and socially, the children will grow up as cousins and the donor couple as aunty and uncle. The gamete donor has also completed a profile of non-identifying information and knows that her identifying information will be recorded on the donor register if a child is born.
- The parties have stated that the counselling provided to them throughout this journey has been culturally appropriate for them.

**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.

**6. Application E24/024 for embryo donation for reproductive purposes**

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 have one biological child and have undergone various attempts to conceive prior to and subsequent to the birth of their child without success. Medical view is that poor egg and sperm quality are underlying this, and that given their lack of success and current ages, embryo donation would offer the couple the best option of completing their family.
- Based on their beliefs and values, the intending parents feel strongly that embryo donation would allow a life already created a chance to continue. They value the opportunity to care for and begin a relationship with a child right from the start of a pregnancy and feel confident that this will help them feel strongly attached to the baby before birth.
- In considering among other things, the factors noted above, the Committee was satisfied that embryo donation offers the couple the best opportunity to complete their family.
- The intending parents view the intended donation as a life affirming option akin to adoption. They wish to have a sibling for their child and if this arrangement is unsuccessful would seek a new embryo donation arrangement.
- The intending mother's medical report did not raise any issues of concern about her medical history.
- The couples understand that all decisions relating to the pregnancy are the intending mothers to make. The intending parents err on the side of pro-life and would only make a decision to terminate if the intending mother's life was at risk. They would care for any child born of this donation, including a child born with a health condition. The couples know that the donors' details will be recorded on the HART donor register.
- The donor couple are from Northern Europe, and they have decided to donate their remaining embryos on the basis that they have completed their own family and, their desire to help others have children. They would prefer that recipients use both embryos and understand the implications of changing their mind between the time an embryo is thawed and transferred. The couple have no shared carrier conditions, they haven't consented to on-donation of the embryos, and they have shared their plans with a small number of family and friends.
- The intending parents have declared that they would look for ways for the child to experience the culture of the donor couple, and the donor couple have indicated that they would be happy to guide a child born of this arrangement. The parties support the right of the child to have ongoing contact with their biological parents and their siblings. The intending parents have shared their plans with family but are yet to do so with their existing child who is still very young. The donor couple's older child knows about the intended donation but has not been involved in counselling sessions at this point in the process.
- The parties have been advised of their consent rights in relation to the intended donation, and the donor couple have not placed any conditions on the donation. The donor couple understand that the counselling conversations are not legally binding and that the intending parents could in future choose to stop contact with them without any legal recourse. The parties anticipate that they will stay in contact and would hope for an extended family type relationship where the donors are socially an aunty and uncle.

## 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.

### **7. Application E24/025 for surrogacy involving an assisted reproductive procedure**

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

#### **Issues discussed included:**

- The Committee was satisfied that the intended arrangement offers the intending parents the best chance to start their family given that the intending mother has a disorder that causes severe growth restriction to a fetus and given the intending mother's history, that the risk of this happening in a future pregnancy is high.
- The intended surrogate is a longstanding friend of the intending parents who has demonstrated a strong commitment to helping the couple have a family and who has made an altruistic offer to act as their surrogate after investigating her own suitability to act as one with her general practitioner. The intending parents' counsellor notes no evidence of undue influence on the surrogate to make this offer to her longstanding friends.
- The important considerations for the surrogate in carrying a pregnancy have been set out in her medical report. Because of her own birthing history, she would elect to have a c-section delivery if this arrangement is successful and her fertility specialists support this. The reports set out that she would have both midwifery and obstetric care during a pregnancy and, that the intending parents would see another midwife and the intending parents would pay for the surrogate's specialist care during a pregnancy. The intending parents have also agreed to pay for the surrogate's life insurance while she is pregnant. The surrogate has noted that if needed, she would take maternity leave early to cover the shortfall.
- The reports detail a strong social support network for the surrogate independent of the intending parents.
- The surrogate has discussed with the intending parents that she would find it easier to terminate a pregnancy in the first trimester should any abnormalities occur. The intending parents intend to have embryos tested prior to transfer and accept the risk that testing would not pick up all potential abnormalities. They would intend to raise any child born of this arrangement. They have approval in principle for an adoption order from Oranga Tamariki and have appointed testamentary guardians in the event they are not able to care for the child and have declared that abnormalities would need to be significant for them to feel comfortable with a termination. Additionally, if the pregnancy presented a serious risk to the surrogate's health, they would support her choosing a termination of pregnancy.

- Both parties have received legal advice and have explored in those sessions the various requirements of the HART Act in relation to surrogacy arrangements and adoption of a child, wills and testamentary guardianship. The counselling report for the intending parents notes discussion around and naming of testamentary guardians and notes that they did not see any circumstance in which they would not accept a child born of this arrangement.
- The intended arrangement has garnered some interest from the media who reportedly contacted the surrogate after spotting that donations were being sought through a crowd funding platform for the IVF treatment costs for the intending parents. The Committee discussed potential privacy issues especially for the existing and potential children and agreed it would not impinge in this space in this case given any decision will be made after the child is born and acknowledging the right of the parents to make decisions about their children. However, the Committee agreed that it would remind the parties about the prohibition in section 14 of the HART Act on valuable consideration.

### **Decision**

The Committee decided to **approve** this application noting its support for the proposed obstetric care for the surrogate, but wished to remind the parties of s14 of the HART Act in relation to the crowd funding media page established for the intending parents, and the associated media interest in the story.

### **Actions**

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

## **8. Application E24/026 for 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 is a single person requiring a sperm donor to begin her family. The intending parent also requires an egg donor due to having a condition that does not allow her to produce eggs. Her sister is the egg donor in this application; she had her eggs collected and stored some time ago with the intention of donating to the intending parent.
- The sperm donor is a clinic donor who had counselling at the time of the original donation. The sperm donor has a history of mild health conditions, and this history has been shared with the intending parent. The sperm donor has moved overseas but remains open to being contacted in the future and has consented to being contacted by children born of this donation.
- The egg and sperm donors have done Invitae testing and do not carry the same recessive genes.
- The egg donor has known for many years that she will help the intending parent by donating her eggs and there is no evidence of coercion in this decision. The

egg donor does not have any genetic children and is the stepmother of her partner's children. The children have been informed of the intended arrangement and are supportive of it.

The egg donor and intending parent feel confident that their extended family will support the intending parent to raise any child. Their family is aware of the donation arrangement and will support a child born of this donation to understand their genetic origins. Both parties intend to be open with a child about their conception story.

- The intending parent has been advised of the risks of carrying a pregnancy with her condition, including the risks of requiring a manufactured cycle prior to the transfer of an embryo and the risk of heart issues. The intending parent had a cardiac MRI and has been assessed by a cardiologist. The cardiologist report noted no reason why it would be unsafe for the intending parent to carry a pregnancy. The intending parent will remain under the care of her Endocrinologist for the duration of any pregnancy and obstetric oversight has also been recommended.
- ECART acknowledged the cardiac risks involved in the intending parent carrying a pregnancy. The Committee discussed the brevity of the cardiologist report and noted that the cardiac MRI was performed in 2019. The report did not provide an assurance that nothing had changed in the intending parent's cardiac health in the years since the MRI.
- The Committee agreed that more information would be needed to accurately assess the risks to the intending parent and how these would be mitigated, including what monitoring she would need and what the risk management plan is required. The Committee also agreed that the intending parent needed to be advised of the risks and, if necessary, to have another MRI.

### **Decision**

The Committee acknowledged the identified risks to the intending parent's cardiac health in carrying a pregnancy. The cardiologist report did not provide assurance of how these risks would be mitigated. Therefore, the Committee decided to **defer** this application to request more information about the intending parent's current cardiac status, including a plan of what kind of interventions she may need for the course of her pregnancy.

Given the significant clinical risk the intending parent's condition poses to her in carrying a pregnancy, the committee would also encourage the intending parent to seek legal advice about wills and testamentary guardianship.

### **Actions**

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

## **9. Application E24/027 for embryo donation for reproductive purposes**

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 had previous unsuccessful treatments using her own eggs and a sperm donor. The donor couple are friends of the intending parent, and have remaining embryos created from their own IVF treatment that they would like to donate to her. The intending parent is at an advanced maternal age and further delays to find an egg donor may reduce her ability to carry a successful pregnancy. Embryo donation is not the intending parent's only opportunity to have a child, however, it is the best opportunity.
- The intending parent has been informed of the risks that advanced maternal age may present to carrying a pregnancy. She is in good overall health with a history of a medical condition that was treated and a supplementary report from her obstetric physician was supportive of her carrying a pregnancy, recommending an early referral to Preterm Birth Clinic once she is pregnant. A plan is in place to support the intending parent through her pregnancy.
- The donor couple have two children and feel their family is complete. One of the donors has mild chronic health conditions and this information has been shared with the intending parent.
- There is no evidence of coercion in this embryo donation. The donors made the offer of embryo donation to the intending parent as a way of allowing them to honour their own fertility journey while giving their friend the chance to try for a pregnancy.
- The intending parent has been informed that once an embryo has been transferred, she has the right to make all decisions about pregnancy, labour, and birth. The intending parent has been informed that she would have the right to make decisions about termination. The intending parent discussed with the donor couple that she would consider termination if the child had a serious disability or genetic disorder, and the donor couple were supportive of this.
- The intending parent has a good network of friends and family who have supported her in her fertility journey and shared that this network would be important in raising any child born from this arrangement.
- All parties intend to be open with any resulting child about their conception story. The intending parent has chosen to use known donors as this will allow the sharing of identifying information and the possibility of a relationship between the potential child and the donors. The parties envisage an extended family type relationship between the potential child and donor family. The donor couple have not spoken about their decision to donate to protect the privacy of the intending parent but intend to tell their children about the donation.
- This is a cross cultural donation. The donor woman is NZ European/Māori and the donor man and intending parent are NZ European. The intending parent understands that the donor woman has not grown up within her Māori culture and that the donor family is exploring what their culture means to them. The intending parent would like any child she has to have knowledge of their Māori heritage and whakapapa. The Committee noted that the intending parent had attended an adoption services session and acknowledged this positive child-centred approach.

### 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.

**10. Consideration of extended storage applications****Meeting close**

Confirmation of next meeting on April 11<sup>th</sup> 2024.

Confirmation of ECART member in attendance at next ACART meeting on February 29<sup>th</sup> 2024, Jeanne Snelling.