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

**27 February 2020**

Held on 27 February 2020

at the Ministry of Health, Wellington

**In Attendance**

Iris Reuvecamp Chairperson

Judith Charlton Member

Paul Copland Member

Michele Stanton Member

Mike Legge Member

Mary Birdsall Member

Mania Maniapoto-Ngaia Member

Kathleen Logan ACART member in attendance

Kirsten Forrest ECART Secretariat

Hayley Robertson ACART Secretariat

1. **Welcome**

The Chair opened the meeting by welcoming all present and noting apologies were received from Mrs Tepora Emery.

1. **Conflicts of Interest**

Dr Mary Birdsall declares (on an ongoing basis) that she is a shareholder in Fertility Associates and has interests on a professional and a financial basis.

1. **Confirmation of minutes from previous meeting**

The minutes from the 12 December 2019 meeting were confirmed.

1. **Application E20/06 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 Surrogacy involving an assisted reproductive procedure* and the principles of the HART Act 2004.

**Issues discussed included:**

* The intending mother has a genetic condition that was diagnosed when she was a child. Specialist advice is that the condition increases the risk to IM in carrying a pregnancy and is supportive of the intended arrangement. The condition does not affect IM’s ability to parent any resulting child. The intending parents plan to have preimplantation diagnostic testing to rule out use of any embryos that carry the intending mother’s condition. They are aware that PGD may show that they have a decrease in the number of embryos suitable for transfer and also of the possibility that a pregnancy might not be established. The birth parents are also aware of this and have indicated that they would be happy for any further testing that the intending parents might want to take.
* The intending parents have indicated that they would like an amniocentesis.
* Both couples are aware that any decisions regarding the pregnancy are legally the birth mothers to make.
* A positive relationship between the intending and birth parents exists. The birth mother and intending mother are sisters; the birth mother does not have same condition as her sister. The birth mother has children of her own and her birth history is uneventful with both of her children being delivered at term without medical intervention. The birth mother has been on medication for to help manage some health issues and her health care service providers report that the issues are well controlled and managed. She has indicated that she will stop taking the medication for the intended surrogate pregnancy.
* The birth mother has been informed of the risks associated with carrying a surrogate pregnancy and that they will be managed with a single embryo transfer.
* Counselling reports indicate that the family is supportive of the sisters and, that the birth mother freely made the offer to IM when she knew that the intending parents wanted to have a family. The relationship they share is described as safeguarding the wellbeing of all parties including that of the potential child.
* The intending parents have declared that they intend to adopt any child born of this arrangement and accept full parental responsibility. In the event that the intending parents are not able to care for the child the birth parents have agreed they would meet with the family for discussion about who would have this role.
* There has been discussion and agreement about pregnancy, birth and post-partum plans; the intending parents would like to be involved throughout the pregnancy while at the same time respecting the birth mother’s privacy and the birth parents are comfortable with this.
* The birth parents have described having support from both sets of parents. The BPs intend to tell their older children and some extended family members about the intended arrangement. The younger children have had counselling and appear to have an understanding of the arrangements around the intended surrogacy including what might happen if the treatment is unsuccessful. The Committee noted that the counselling of the children was particularly well done in this application.
* Both couples have received counselling and independent legal advice reporting conversations around the issues of formal adoption, guardianship, no financial exchange, insurance for the birth mother.
* The intending parents are well-supported and understand the process including PGD. The birth parents are in good health and any challenges to psychological well-being are being well-managed.
* In relation to the timing of organising guardianship it was not clear to the Committee whether there is a clear understanding of the distinction between guardianship and custody. There is mention of having guardianship orders put in place when it is determined there is a need for them and depending on who is willing and available to look after a child. However, they could put orders in place now that don’t compel the appointed person to have responsibility for day to day care of the child.
* Individual counselling for IPs states that they wish to have an amniocentesis and that they would raise this at the joint counselling session to see whether BM is happy to have invasive testing during a pregnancy. However, the joint counselling report doesn’t mention any discussion in relation to this.
* This may be due to them receiving advice that PGD cannot guarantee 100 percent accurate results or to check the number of chromosomes in the baby. The reports don’t give ECART this information and in this case ECART agreed that it didn’t need to know this in order to make a decision.

**Decision**

The Committee agreed to **approve** this application with an explanation noting how testamentary guardianship works with a suggestion that the parties consider this further.

**Actions**

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

1. **Application E20/07 for Surrogacy involving an assisted reproductive procedure**

Paul Copland opened the discussion for this application. The committee considered this application in relation to the *Guidelines on Surrogacy involving an assisted reproductive procedure* and the principles of the HART Act 2004.

**Issues discussed included:**

* This is the second application to ECART for the intending parents. ECART approved the first application with a different surrogate and that arrangement was successful and a healthy child born who the intending parents have legally adopted.
* There is a focus in this application on the proposed birth mother who has offered to act as a surrogate and her relationship to the intending parents; there is a familial link. The medical report for the birth mother gives no indication against her carrying a pregnancy and there appear to be no significant risks to her or the potential child.
* The birth mother has previously considered acting as a surrogate but wanted to wait until she had completed her family, which she and BP have done now.
* The Committee had no concerns about the social aspects in relation to this application: the couples share close and supportive relationships and are and intend to be guardians to each other’s children. The existing children play together, and they look after each other.
* The Committee noted a concern that the birth mother may not have a clear understanding of her rights in relation to consent given the wording of a statement at section 5.10 of the application that states: “BM confirmed she understood that she can withdraw consent to proceed at any time until [an] embryo is replaced.” The birth mother could withdraw her consent including during the pregnancy or after the child is born (at which point it could go to court). However, there was nothing else in the application that indicated that there were any concerns or unclear understanding in relation to this.
* As this is the intending parents’ second application their lawyer provided a brief update saying the advice is the same. There is no requirement to ask for a new legal report given that the advice has not changed, and the intending parents are familiar with the legal issues having had a successful adoption with their first child born of a surrogacy arrangement.

**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.

1. **Application E20/08 for Surrogacy involving an assisted reproductive procedure**

Mike Legge opened the discussion for this application. The committee considered this application in relation to the *Guidelines on Surrogacy involving an assisted reproductive procedure* and the principles of the HART Act 2004.

**Issues discussed included:**

* The Committee noted notification received just prior to the meeting from the clinic that advised the intending mother is scheduled to have a hysterectomy in the near future and, agreed that it does not require confirmation beyond the clinic letter.
* The intending mother has one child. Her previous pregnancy was complex and while she was being treated developed a syndrome which meant she could not receive certain aspects of care.
* The intending mother’s child has a condition and, the intending mother and her child are well-supported by family in helping with practical care. Extended family members will be appointed testamentary guardians of both her existing child and her potential child once born.
* The birth mother has children and her pregnancies and deliveries were without complication. She has had the risks of potential complications of a surrogate pregnancy explained to her.
* The birth mother has practical support in place for her pregnancy. One of the birth parents’ children has a condition that is well managed, and they don’t anticipate that the child will have any issue with the surrogacy arrangement.
* The couples are long standing friends who are in regular contact. They have discussed and agreed birth plans, are aware of conflict resolution processes should they need them, and the birth mother is aware of surrogacy arrangements and conditions that apply to surrogacy.
* Oranga Tamariki have approved an adoption order in principle.

**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 advice.

1. **Application E20/09 for Donation of sperm between certain family members**

Michele Stanton opened the discussion for this application. The committee considered this application in relation to the *Guidelines on Donation of Gametes between Certain Family Members* and the principles of the HART Act 2004.

**Issues discussed included:**

* The recipient woman’s brother in law has offered to donate sperm to her and her partner. The initial plan is to have treatment using IUI and, if this is not successful, then the creation of embryos and IVF.
* The RP is a transgender man hence who was born a biological female and hence the couple require donor sperm. The couple are in a longstanding relationship and have always known that they would need donated sperm to help them start their family.
* The recipient woman has had a medical specialist explain that she would have the same baseline risks as any other woman of her age going through IVF. There are no known additional risks to her.
* The sperm donor is in excellent health with no personal or family history relevant to the donation. He is a New Zealand citizen and his partner have two children and they currently live offshore. The recipient couple were born offshore and have indicated that they may move back to their country of birth. They have been living in New Zealand for the past few years. The two families get together a few times a year.
* There is no evidence of coercion: a discussion about a possible donation began around a couple of years ago and between the recipient couple and then the sperm donor spoke with the recipient woman. The sperm donor has consented to donate only to the recipient couple.
* The Committee is told that wider family were very supportive of RP’s gender reassignment and are very supportive of how the couple can have a family through sperm donation.
* The sperm donor and sperm partner are aware that counselling is available for their children should the need arise, and they are happy to be guided by the recipients. This is one aspect that may need to be reconsidered given that the literature says that children, ideally, shouldn’t remember the time when they are told of their origins. However, they are aware that counselling is available, they expect any resulting child to be made aware as and when appropriate and they will begin dialogue with their children with guidance from the recipients.
* Relevant legal information has been covered off including consent issues and the right of the child to obtain identifying information at 18 years of age should that information not have been provided prior.

**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.

1. **Application E20/10 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 Embryo donation for reproductive purposes* and the principles of the HART Act 2004.

**Issues discussed included:**

* The recipient woman is a single woman. She has a child and would like to complete her family and have a sibling for her child. She has accepted that she will have no biological link to the resulting child. Her medical report states she is fit and well and her previous pregnancy and birthing history is uneventful. The risks to her in carrying a pregnancy using a donated embryo have been noted and discussed.
* The recipient woman presents with a number of health factors that could present challenges, but they are manageable and have been covered off in section 3.13 of the application. Her BMI is not ideal, but she has had a reasonable outcome with her previous pregnancy and has a healthy child.
* The donor couple have children and their family is complete. The two embryos they wish to donate to the recipient woman were created through IVF for the donor couple’s fertility treatment.
* The recipient woman has yet to receive police vetting and any ECART approval would be subject to this being completed with no concern noted so that the guideline requirement can be met.
* The parties initially met via social media but have since met in person. The donors have noted that they would like to have a friendship with the recipient woman in future. There has been declared intention that their existing children and the potential child will be made aware of the donation. The recipient woman’s child’s biological father is a sperm donor and the child is aware of this who the father is.
* The Committee noted at the time the donors were seeking counselling in relation to this donation they hadn’t met the recipient woman and seemed non-fussed about doing so and then when they did meet her in the joint counselling session they reported being happy to meet her and to learn that she has similar values which seemed a little unusual but the Committee had no substantive comments in relation to this.
* The joint counselling report notes that the donor couple are happy donating to a single woman as they want to donate to someone who they feel matches their values and ideas.
* The recipient woman has strong family and friends support networks.
* Each party has received independent legal advice and have discussed the legal issues associated with embryo donation.
* The Committee queried the ages of the donor couples’ children as the ages stated appear too young given the donor couple are reported to have looked t to donate a few years ago and clinic policy is that donors typically wait around two years before considering the option to donate. The Committee noted that it appears the ages have been transposed from a 2017 application that ultimately wasn’t submitted to ECART. The fact that the children are older now raised the question for the Committee as to why they have not been involved in counselling.
* The Committee noted what seems like a reasonable time lag between the initial individual counselling and the joint counselling but accepted that this may have been due to when it suited the applicants.

**Decision**

The Committee agreed to **approve** this application and to note there is some inaccuracy in the stated ages of the children do not appear to be correct and what the Committee assumes the ages in fact are.

**Actions**

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

1. **E20/11 application for Embryo donation for reproductive purposes**

Iris Reuvecamp opened the discussion for this application. The committee considered this application in relation to the *Guidelines for Embryo donation for reproductive purposes* and the principles of the HART Act 2004.

**Issues discussed included:**

* The embryo donors don’t affiliate with a religious base. They have one child and appear to be reasonably definitive about their decision not to have any more children. Given the age of their child, the question was raised as to whether the decision to donate has been made too soon.
* The counselling report for the donor couple notes that the donor woman’s age at the time of egg collection fell outside the guidelines for donation to recipients on a waiting list. A post placed on a social media page by the couple, received multiple responses and the donor couple were drawn to the recipient woman’s application. The Committee discussed the extent to which the approach might raise any concerns for ECART.
* The donor couple are abiding by the principle that they want to pay-it-forward and donate their remaining three embryos to the recipient woman.
* The recipient woman is infertile after receiving medical treatment for illness. Her health care providers are supportive of her pursuing fertility treatment.
* The donors understand the legal aspects of the donation and are comfortable that the recipient woman is aware of who they are. They anticipate that a child may want to know more information about their genetic sibling and are happy for that to happen depending on what the need is. They are willing to share health information that might be relevant. They understand that not all embryos may be used and in that case are happy for the recipient woman to make decisions around disposition of the embryos.
* The donors feel ready to explain their choice to their own child and hope that she will get to know both the recipient woman and her child from a young age.
* Police vetting hasn’t been completed and ECART agreed to say that in any decision letter approval is subject to that happening.
* The donors met the recipients online and they have been in regular contact since. They have had discussions about contact, maintaining contact and the relationship in the future. The recipient woman has declared that she would like to stay in contact and that she would like the child to have contact with the donors and the donor’s child if everyone felt that was appropriate.
* The recipient woman is well supported by family and friends who are aware of the proposed donation. She has said that she is unsure about whether she would want a second child and the parties have agreed that disposal of the embryos if needed would be okay.
* Both parties have obtained legal advice. They all understand that consent can be withdrawn before embryo transfer, including a situation where there has been a successful pregnancy and there may be embryos left and the donors then withdraw their consent. The donors know that the legal rights reside with the recipient woman during any pregnancy she may carry.
* The Committee noted that given the donor woman’s age at the time the embryos were created meant that they fell outside the guidelines for donation ECART would want to be clear that the recipient woman knows about that and the reasons why (that they have been expressly outlined to her).
* The Committee discussed approval of the application subject to the condition that transfer cannot take place until the donor couple’s child is at least 2 years old so that the donor couple can reconsider their decision to donate at that time. The Committee agreed it would also seek reassurance that the chances of successful treatment with these embryos have been discussed with the recipient woman given the donor woman’s age at the time the embryos were created and the fact that this excluded the donor couple from being able to be clinic donors.

**Decision**

The Committee agreed to **approve** this application subject to an embryo transfer not taking place until the donor couple’s child is at least 2 years old to help reassure the Committee that the donors are absolutely clear that this is the right decision for them.

The Committee also seeks reassurance that the recipient woman has had the reasons for the donor couple’s embryos not being eligible for the general clinic waitlist for donations expressly outlined to her.

**Actions**

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

1. **E20/12 application for Surrogacy involving an assisted reproductive procedure and donor eggs.**

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

**Issues discussed included:**

* The intending mother has had a hysterectomy and oophorectomy following a diagnosis of cancer and had subsequent chemotherapy and radiotherapy. The only option open to this couple is donor egg and surrogacy. The IM has recently been discharged from specialist care as medical opinion is that she is essentially cured.
* Two embryos already exist. The egg donor has had one cycle of IVF for the purposes of egg donation for the intending parents and she is prepared to do a further cycle. She had no complications as a result of egg collection.
* The egg donor is positive for a heritable genetic condition, but the intending father is negative.
* BM has one child from a previous relationship who was born by caesarean section delivery. The birth mother’s current partner has declared that he has no wish to have his own genetic child and he has no children from previous relationships. The couple have had the risks of surrogate pregnancy and birth explained to them.
* The donor couple met the intending parents online and corresponded for some months before the egg donor made her offer to donate. They have met in person and think they share similar values and understanding of the intended surrogacy arrangement. The egg donor understands that a surrogate is required, and she and her partner are comfortable with that.
* The donor couple have a number of children between them both together and from previous relationships. They plan to tell their children and they have already discussed the planned arrangement with their older children and plan to be open and honest with their younger children at an age appropriate time. They didn’t currently feel that counselling is necessary for their older children.
* The donor couple are open to future contact with the intending parents and the children in the future and would wish to be seen as extended family. The donor couple are happy to be identifiable and they understand that the decisions around surplus embryos and around TOPs are not theirs to make.
* The birth mother has completed her family and she has told her child about the intended arrangement. She and BP moved to New Zealand around a year ago and are living in New Zealand with extended family. The relationship between the birth mother and intending mother is that of close cousins. They grew up in the same place together offshore and share many close friends. The offer from the birth mother to act as a surrogate was made spontaneously and without coercion.
* The birth couple know about the use of an egg donor and the birth mother understands that the decisions around TOP ultimately rest with her, but she feels that they will defer to the intending parents for decisions around that.
* Both couples have sought independent legal advice and have been informed of the adoption process and the law associated with a surrogacy arrangement.
* The intending and birth parents describe shared background and cultural beliefs and in relation to the difficult topic of termination of pregnancy agreed that the birth mother’s health is the most important parameter, and everyone is clear that they would not reject a child. The intending parents will ensure that testamentary guardianship is in place prior to embryo transfer. Oranga Tamariki has approved an adoption order in principle.
* The birth parents are in the process of seeking permanent residency and have been advised that the baby, if born in New Zealand will be a New Zealand citizen. The immigration process would take around 9 months and they might still proceed with embryo transfers provided that they have enough time left on their current visas for the adoption process to be completed. They are clear that they don’t want to have the potential baby offshore because of the potential complications that will arise around trying to get the baby back to New Zealand.
* ECART is required to consider residency including in the context of a child having access to knowing where they have come from genetically. The arrangements appear stable in terms of the welfare of the potential child, but the timing of the planned treatment and their as yet uncertain longer-term immigration status seems tight. It seems that they’d need to establish a pregnancy within the next two months. The Committee discussed requiring that the birth parents don’t start treatment until they have permanent residency in New Zealand.
* In this case, because there are some complex relationships and scope for things to go wrong, ECART agreed to defer the application until residency is gained.

**Decision**

The Committee agreed to **defer** this application until residency is gained to ensure the best interests of the child are safeguarded.

**Actions**

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

1. **Application E20/13 for Surrogacy involving an assisted reproductive procedure**

Mike Legge opened the discussion for this request. The committee considered this request in relation to the *Guidelines for Surrogacy involving an assisted reproductive procedure* and the principles of the HART Act 2004.

**Issues discussed included:**

* The intending mother has a long and difficult history of unsuccessful pregnancies. The intending parents have three embryos in storage which have had PGTA testing.
* The intending parents and surrogate have all had genetic counselling in relation to the embryos and there is a shared agreement to use the one quality embryo in treatment.
* The birth mother has children and has completed her family. Each of her pregnancies and births were uneventful and her general medical history is without complication and she is in good health.
* The birth mother and intending mother are related and are in close contact. They are comfortable with the pregnancy and birth plans and the agreement is to do an embryo transfer using the one quality embryo. They may consider using the low-level mosaic embryo.
* Both parties had difficulty in considering termination but agreed they would consider it in the event the baby would be born with a serious and life-threatening abnormality.
* Testamentary guardianship has been discussed and agreed and Oranga Tamariki has approved an adoption order in principle.
* The Committee noted that mosaic embryos are being used more and more and with healthy babies born. Here and internationally fertility treatment providers are seeing 30% live birth rate with the use of mosaic embryos with no increased risk of genetic abnormalities for those children. In terms of transfer rates of mosaics, it is not known exactly how the mosaics will affect outcomes of pregnancy, but it is known that there are successful outcomes from mosaic pregnancies.
* In this particular case, ECART sees no problem with the intended surrogacy arrangement and does not think the surrogate will be at any greater risk. The Committee noted that the clinical decisions about which embryos are to be transferred are up to the clinicians and genetic counsellor and surrogate. It has been made clear to ECART that the high mosaic embryo will not be transferred.
* The Committee noted that the birth mother’s three oldest children have not had counselling. The reports state that she has talked to her eldest three children and will build on that information as plans evolve. The children are described as being excited about bringing another baby into the family. ECART noted it is required to look after best interests of children in that family. A skype counselling session is planned and ECART could encourage them to take the opportunity for access to counselling.
* The letter from Oranga Tamariki provides a recommendation around grief and loss which is unusual.
* 1.14 – approving use of mosaic or make clear that is a clinical decision? ECART notes that there are three embryos, there is no issue with using the first, that the use of second with low mosaicism is a clinical decision in conjunction with all parties. In relation to the third embryo ECART notes its understanding that this will not be used.

**Decision**

* The Committee agreed to **approve** this application refer to OT recommendation, encourage older children to have counselling. Relationship counselling is of note for the letter – very well done.
* Recommend that they make the decision on use of the other two embryos in conjunction with their clinician and genetic counsellor.

**Actions**

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

1. **Application E20/14 – Application for Surrogacy involving an Assisted Reproductive Procedure**

Michele Stanton introduced this response. The committee considered this application in relation to the *Guidelines on Surrogacy involving an Assisted Reproductive Procedure* and the principles of the HART Act 2004.

**Issues discussed included:**

* The intending mother’s medical history and treatment has resulted in her being advised not to carry a pregnancy due to high obstetric risks to her and to a potential child. Therefore, the option of a surrogacy arrangement is the best or only option for her and her partner to have a family. The couple had embryos created prior to IM’s medical treatment and these embryos will be transferred to the birth mother should ECART approve this application. The intending parents have indicated that they would like to have one child and, should there be any surplus embryos following treatment, they would wish for these to be discarded through the clinic process.
* The birth parents were not born in New Zealand but have residency here and they intend to stay in New Zealand. They have completed their own family and the birth mother’s pregnancy and birthing history is uneventful.
* The couples have known each other for some years, they see each other regularly and they share similar values. They each describe the relationship they share as close and like family. Both couples describe that being migrants to New Zealand with most of their extended families offshore has made the bonds of their friendship closer.
* The birth mother and birth partner appear to have freely made the offer to be surrogate parents for the intending parents and there is no suggestion of coercion.
* The intending parents intend to adopt a child born of this arrangement and have started the process with Oranga Tamariki for approval of an adoption order. A letter from Oranga Tamariki has been promised to ECART once it is available (pending both offshore and New Zealand police checks).
* There has been discussion and understanding between the couples regarding their intentions about day to day care, guardianship, adoption and ongoing contact. They have also had discussions around the difficult topic of termination of pregnancy and are in agreement about when they would and would not opt for this.
* Each party has received independent medical and legal advice and they appear to clearly understand the legal issues associated with surrogacy.
* One of the birth parents’ children has received age appropriate counselling and support. They know that further counselling is available, and this will be taken up as required
* ECART is told that the intending mother has had a complete response to treatment with no clinical recurrence. In joint counselling sessions the couples have had discussion around what they would do if the intending mother’s condition returned and also if a prognosis was terminal. Both parties declared that they would be happy to proceed with the intended arrangement and would trust the intending father to be sole guardian of the potential child.

**Decision**

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

**Actions**

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

1. **Application E20/15 for Surrogacy involving an assisted reproductive procedure**

Mary Birdsall introduced this response. The committee considered this application in relation to the *Guidelines on Surrogacy involving an Assisted Reproductive Procedure* and the principles of the HART Act 2004.

**Issues discussed included:**

* The intending parents in this application have children and would like to have one more child to complete their family. They have embryos in storage and any child born of this arrangement would be genetically related to both intending parents and a full-sibling to their existing children.
* One of the intending parents’ children was born using the surrogate and the child was born in early 2018.
* Before the birth mother was a surrogate for the intending parents, she and her partner had two children and both pregnancies and births were uncomplicated. With the surrogacy pregnancy she had a fast delivery and there were some postpartum medical issues that were challenging for all but were neither life threatening nor ongoing. Because of this experience, the couples have agreed on a change in birth plan for the birth mother should this treatment be successful.
* The couples have maintained good relationships since their previous surrogacy arrangement. They found that the legal and adoption process went smoothly.
* Testamentary guardians are in place for the intending parents in the event that they are unable to care for the child.
* The birth mother has significant endometriosis but has been pain free for the past 6 months and this is why she is happy to go ahead with the intended surrogacy. Her previous experience as a surrogate went well apart from the birth being slightly traumatic due to a unique set of circumstances in relation to the care she received during the delivery. There are plans in place to improve on this this time around.
* Repeat counselling of both interested parties, both individual and joint sessions and there are no new issues raised.
* The parties haven’t visited their lawyers again as there are no new legal issues since their original legal reports were submitted as part of their original application.
* A letter from Oranga Tamariki has been submitted but this is in relation to their previous surrogacy arrangement and ECART would like to see a letter in relation to the current arrangement.

**Decision**

The Committee agreed to **approve** this application subject to receipt of a letter from Oranga Tamariki that approves an adoption order in principle.

**Actions**

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

1. **Application E20/16 for Human Reproductive Research**

Paul Copland introduced this application. The committee considered this application in relation to the *Guidelines for Research on Gametes and Non-viable Embryos* and the principles of the HART Act 2004.

**Issues discussed included:**

* When embryos are created and incubated in the lab standard practice is to do imaging of the embryos. Images are periodically taken at different levels and large amounts of data generated which is in the form of different images of the embryos at different times. What this research proposes to do is to use this data to train a deep learning computer system. (Deep learning is most commonly known for its role in image analysis where an image is broken down into component parts and this makes it easier to analyse the connections between different parts of the evolution and, also potential outcomes). In this case, the outcome will be which embryos presumably result in live births and which ones didn’t.
* In machine learning connections can be drawn between things that wouldn’t necessarily seem to be related on a statistical basis resulting in counter intuitive results that work really well. Because the process is not logical or rational but rather correlational, it could be that there is something that signifies an embryo is ‘good’ that a human would never pick or observe. The technology is interesting and if the data is able to be used to see which embryo is best then people increase their chances of getting pregnant which is the desired outcome.
* The consideration for ECART is whether the application falls within its jurisdiction.
* Health Legal in its advice to the Committee has applied a consistency approach. They have been asked to determine whether this research falls within the ambit of human reproductive research/whether it sits within ECART’s jurisdiction. Health Legal has always adopted a broad definition of use and consistent with that in its current advice is that, at a stretch, ECART could adopt the view that this application is human reproductive research. The advice given states that ECART has the discretion to decide whether the research involves use of the embryos.
* Some of the arguments are saying use should have a broad interpretation that allows for any kind of research in any way related to human reproductive technology and should come to ECART for consideration. There is an attraction to that argument for ECART as it would like to see any research that relates to assisted reproductive technology and would want to be the ethics committee that determines that.
* ECART would wish to see reproductive research being performed in New Zealand in an ethical way to improve the general knowledge base in this area. ECART agreed it would be useful for the committee to consider this proposal, but it is limited by the current guidelines. If it were to apply a broad definition of use that achieves this aim. The issue is however, that if the broad definition of use is applied and all applications do come to ECART then it is limited by guidelines it has as it virtually cannot approve any applications.
* The definition of Human Reproductive Research is: *“Research that uses or creates a human gamete, a human embryo or a hybrid embryo.”* This research is no different to research that involves retrospectively looking through medical records. While ECART would like to consider this type of research the legislation doesn’t apply in relation to this particular case.
* The Committee’s view is that it is the *collection* of the data through the standard clinical process of imaging that constitutes the ‘use’ of the embryo. This research will use retrospectively collected data and will therefore not use the embryo.
* In that context the Health Information Privacy Code allows for information to be used without prior consent provided that it is used in a form in which the individual concerned is not identified, it is to be used for statistical purposes and will not be published in a way that could reasonably be expected to identify a person or, it is to be used for research purposes for which, approval by an ethics committee if required, has been given and will not be published in a form that will not reasonably be expected to identify the individual concerned.
* Embryos are not legally individuals as they don’t have any personage until such time that a baby is born so ECART is looking at information that relates to the gamete donors/owners’ medical records. This is about accessing health information rather than using embryos.
* Therefore, the research doesn’t fall within ECART’s remit and ECART would suggest that the application is considered using the usual processes that apply for research involving access to medical records without their specific consent.

**Decision**

The Committee agreed to write to the research team to advise that it is of the view that the intended study doesn’t fall within ECART’s remit for review as it doesn’t involve the use of embryos but rather images related to an embryo that have already been collected. Because it is not research that: *uses or creates a human gamete, a human embryo or a hybrid embryo* it does not fall within ECART’s jurisdiction.

**Actions**

Secretariat to draft a letter from the Chair to the research team and to also make position clear to ACART that it thinks ECART should be able to broadly consider research applications for assisted reproductive technologies, but its hands are tied given the limitations of the current ACART guidelines.

**Correspondence**

Letter from a fertility provider in relation to an application for surrogacy where a baby was born of the arrangement and the parties would like to submit a new application with the same surrogate. The provider has asked what ECART would expect to see in a new application. ECART will respond advising that it would like to see updated medical reports for the birth mother and the intending mother, updated counselling reports for both parties. ECART would not need to see updated legal reports.

**General business**

Workshops in relation to Terms of Reference and also to look at application forms consistent with the new ACART guidelines and the online application platform ERM. The Ministry is seeking ECART representatives (2-3) to attend the workshops which are planned to start in April 2020.

There will certainly be representation from ECART at those meetings and once more detail is provided around what will be involved ECART can commit to that.

ECART still has a situation where the daily rate remains unchanged and particularly for people who are self employed that is quite a commitment.