ARP 20813 for embryo donation

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

- The subcommittee summarised the situational factors of this intended embryo donation. The intending parents are based in New Zealand and the embryo donors, their friends, live offshore. The intended donation has been made in the context of the friendship the two couples share.
- The donor couple have twins born from their embryos created for their own IVF treatment and consider their family to be complete. They wish to donate their 3 remaining embryos to the intending parents.
- When ECART originally considered this application it noted that some of the donor woman's medical history was raised and discussed in the counselling report. The report discussed a genetic condition (Reeds Syndrome), noting that it is not likely to be heritable and, has not been seen in the donor couple's children. The medical reports did not mention the condition and the Committee noted that the genetic counselling had identified the condition as autosomal dominant. The Committee agreed at that time that given the condition is autosomal dominant, and that there may be a 50 percent chance that the remaining embryos carry the gene, which is associated with a higher risk than the general population of developing renal cancer, that it would defer the application to seek further clarification and information about the condition and its implications for the embryos and potential child, and a reassurance that the intending parents are aware of any relevant new information before making a decision.
- The response before the subcommittee confirms that the donor woman has the autosomal dominant gene mutation, which is heritable and, which means that there is a 50% chance the embryos created could be affected. The donor couple have received genetic counselling offshore and, the intending parents have seen the genetic counsellor's report and have been well-counselled in New Zealand about the associated risks and implications for the potential child. A letter from the intending parents submitted with the response confirms they have considered and accept the risks and consequences and still wish to proceed with the intended arrangement.
- ECART had originally noted the intended donation was not the only opportunity for the intending parents to complete their family and, had accepted the reasons stated by the intending parents that it was the best opportunity. However, the subcommittee discussed whether, in light of this new information and the noted implications for a future child, it was still of the view that this is the best opportunity given the gametes of one of the intending parents could be used. In that case, there would be a genetic link and no known risk to the future child developing the condition.
- It was noted that a future-affected child could have a 7.5-9 percent chance of developing renal cancer and, that even though screening is available, the survival rate is not high. The intending parents are aware of the risk, have not

chosen to have the embryos screened before implantation and, are still willing to proceed.

- The sub-committee noted a reluctance to make a judgement call on the quality of life for a person who carries the mutation or to say that the best interests of the future child would be compromised in a material way by carrying this risk.
- In weighing the factors noted above, the subcommittee consensus was ¾ towards approving the application.

Decision
The subcommittee agreed to include this reponse on its April 2025 meeting agenda to note that the subcommittee consensus is toward approving this application and to seek consensus agreement before doing so.

Actions
Secretariat to assign response to the ECART's April 2025 meeting and, to contact clinic to advise that the response will be further considered by the full committee before a decision is made.

ARP 21049 for clinic-assisted surrogacy with egg donation

The subcommittee 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.

- In its original consideration ECART agreed to defer this application to request a more comprehensive legal report for the surrogate that would address in greater detail, the legal advice and information that was provided to her and her partner in general, in terms of the cross-border nature of the intended surrogacy arrangement.
- The Committee was seeking an assurance that the surrogate was aware of the risks inherent in a cross-border adoption process where jurisdictions differ. While the response did not expand on that, it noted that the parties plan is for the intending parents to adopt the child in New Zealand so they will have adoption papers to evidence they are the child's legal parents when they enter other countries. The subcommittee noted that the adoption process will take time so there are layers of uncertainty in relation to whether all would go to plan in relation to intended timing for the adoption. The subcommittee was reassured however, that Oranga Tamariki have assessed and approved an adoption order in principle.
- The Committee also requested a support plan for the surrogate that would set out how the parties would communicate and, how the health and wellbeing of the surrogate would be protected during the surrogacy.
- While the plan provided does not specifically address what might happen if the adoption process is delayed, it does note that the surrogate is aware of what she is agreeing to and that any transfer of parental status will happen with the adoption process and she has agreed to take on this risk. Letters from the intending parents provided reasurance for the subcommittee that the surrogate will have extra support from the wider whānau around her.

- ECART also noted that any subsequent decision to approve this application would be conditional on the use of IP1's gametes only as IP2's clinical information had not been disclosed to the egg donor at that time.
- While the wording in a letter from the egg donor was vague, the subcommittee agreed that it would place trust in the clinic to have passed on ECART's letter and information. It was therefore satisfied that the transparency issue has been addressed. It also noted there is no material risk to the surrogate around the use of IP2 gametes to create the embryos and, this application is for the use of IP1 gametes.

Decision
The subcommittee agreed to **approve** this application

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