

ACART Consultation Document

Proposed Donation Guidelines: for family gamete donation, embryo donation, use of donated eggs with sperm and surrogacy.

Genea Oxford Fertility

General Comments:

Genea Oxford believes that the proposed amendments to the ACART guidelines (above) are positive. The amendments will improve access to treatment through New Zealand Fertility Clinics and help keep pace with changes in IVF technology.

We acknowledge the scarcity of New Zealand egg and sperm donors and feel there should be some thought as to how we can improve information to prospective donors to increase availability.

We do not feel that offering donated embryos will solve this problem.

Question 1: Rescinding the biological link policy

ACART is proposing that:

- the guidelines should no longer require intending parents to have a genetic or gestational link to a resulting child
- instead the guidelines should require ECART to be satisfied that where intending parents will have neither a genetic nor a gestational link to a resulting child, the lack of such links is justified.

Genea Oxford agrees to the removal of the requirement for the biological link but believes that expectations and relationships amongst individuals must be carefully managed with counselling prior to and during treatment, if deemed necessary.

The document mentions other jurisdictions that have adopted rescinding the biological link, but doesn't state the outcomes for individuals involved. The resulting document needs to be more evidence based to be sure that there are not negative outcomes in these areas, and that the studies on wellbeing are old enough to be valid.

Perhaps increasing guidance or training opportunities for Fertility Counsellors could help to improve the consistency of counselling advice, with documentation provided to, and recorded about, individuals accessing these treatment options.

Question 2: Access to information held on birth certificates

Genea Oxford agrees that strengthening access by donor offspring to information about their origins can only be a good thing. Is there a possibility for links to the Fertility Clinic to be made on birth certificate records?

Question 3: Format of the proposed guidelines

ACART is proposing to issue one set of guidelines to ECART that encompass family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic-assisted surrogacy. Genea Oxford agrees with the proposal for one set of guidelines. Highlighting the counselling requirements would be very helpful. This would be especially so if it is ECART's intention for counsellors to make a recommendation about the application to ECART as part of the submission process.

Question 4: Justification to use a procedure

ACART is proposing that ECART should be satisfied the proposed procedure is the best or only opportunity for intending parents to have a child and the intending parents are not using the procedures for social or financial convenience or gain. Genea Oxford agrees with this. The document acknowledges that some cases are complex and Medical Specialists and Counsellors are well placed to document the reasons for wishing to proceed with treatment.

Question 5: Consent by gamete and embryo donors

ACART is proposing that where a procedure will involve the use of an embryo created from donated eggs and/or donated sperm, the gamete donor(s) must have given consent to the specific use of their gametes:

- at the time of donation; or
- when a procedure using such an embryo is contemplated.

In either case, the affected parties should receive counselling, on the implications of using gametes, before the gamete donor gives consent.

If consent is given, the gamete donor can vary or withdraw their consent only up until an embryo is created (in cases where consent is given before the embryo is created).

Genea Oxford feels that consent should be taken at the time of donating a gamete and should not be sought for each embryo transfer procedure after this initial consent. The latter option would be overly intrusive to gamete donors and would give information on the success, or lack of success, of the recipient couple. Consent at the outset gives clear information about what the donor is consenting to, and is an opportunity to clearly define what procedure the donor is undergoing.

In addition, where a procedure will involve the use of a donated embryo, the person(s) for whom the embryo was created must give consent to the specific use of the donated embryo:

- at the time of donation; or
- when a procedure using such a donated embryo is contemplated.

Once an embryo is created, the decision to vary or withdraw consent up to the time the embryo is transferred to the womb should remain with the people for whom the embryos were created. As above, consent should be made at the time of embryo donation and not continued for each transfer procedure. This clearly defines the role of each party.

Question 6: Taking account of potential coercion

ACART is proposing that ECART should take account of any factors in a relationship that might give rise to coercion or unduly influence the consent of a donor or surrogate to a procedure.

Genea Oxford agrees, but the basis of coercion is emotional, so this needs to be highlighted too.

Question 7: Limit to number of families with full genetic siblings

ACART is proposing that full genetic siblings should continue to be limited to no more than two families. Genea Oxford strongly agrees that full biological siblings should be limited to only two families.

Question 8: Legal advice

ACART is proposing that ECART must be satisfied that:

- where an application includes a surrogacy arrangement, each affected party has received independent legal advice
 - where an application does not include a surrogacy arrangement, each affected party has considered seeking independent legal advice
 - any legal reports show that all affected parties understand the legal implications of the procedure(s).
- Genea Oxford agrees that legal advice is best given by lawyers and situations that require applications to ECART are likely to be more involved or complex so the suggestion that legal advice be sought if wished can only be helpful at the outset.

Question 9: Regulation of all family gamete donations

ACART is of the view that all family gamete donations through a fertility services provider should be regulated by guidelines and thus require ECART approval.

Genea Oxford agrees – family gamete donations are complex.

We acknowledge that there are resulting workforce issues and costs to consumers as a result of this change; there is likely to be an increased cost to New Zealanders using these treatments and the need for more counsellors if changes are implemented.

Question 10: Donation of embryos created from donated gametes

ACART is proposing that the guidelines should enable ECART to approve the donation of embryos created from donated eggs and/or donated sperm, provided ECART takes account of the potential complexity of resulting relationships, and the gamete donors have given consent to the specific use. Genea Oxford disagrees with this proposal on the basis of the potential for gamete donors to feel compelled to consent to recipients wishing to on-donate surplus embryos created with their gametes to someone else rather than destroy them. It has the potential to place the gamete donor in a vulnerable position – feeling forced or compelled to agree with procedures they may not be comfortable with.

There is a considerable trust relationship between gamete donors and the fertility clinic that could be jeopardised if recipients have the potential to change the terms of the donation at some point in the future.

Counselling for this potential at the outset of gamete donations is complex and may cloud or confuse how many recipients the donor is donating to. This becomes even more complex in situations which include two independent gamete donors; the risk to resulting children, from the increased complexity of any resulting relationships, is too great.

Question 11: Embryo on-donation and re-donation

ACART is proposing that surplus donated embryos:

- should not be able to be on-donated by the recipients
- but can be returned to the donors, in accordance with any agreement between the parties, for re-donation to another party, subject to a new approval by ECART.

Genea Oxford agrees as long as the two family rule is upheld. However ACART needs to explain the rationale for 're-donation'. For instance, is it only in cases where the donation doesn't result in a live birth for the recipient couple?

Question 12: Clarification of the status of embryo donation in the regulatory framework

ACART is of the view that the regulatory framework should clarify that:

- all embryo donation cases are regulated by guidelines and thus require approval by ECART
- embryo donation does not include cases where an embryo created for one couple is used by one of the couple in a new relationship with the informed consent of the previous partner.

Genea Oxford agrees.

Question 13: Regulation of all clinic-assisted surrogacies by guidelines.

ACART proposes to recommend that all clinic-assisted surrogacy cases be regulated by guidelines and thus require ECART approval.

Genea Oxford agrees with this proposal.

Thank you for the opportunity respond to the request for submissions, and the opportunity to meet with representatives from ACART and the Ministry of Health as part of the preparation of our submission.

The Genea Oxford Fertility team