PIVET Medical Centre

DONOR EMBRYO INFORMATION



PIVET MEDICAL CENTRE ASSISTED REPRODUCTIVE TECHNOLOGY PROGRAM

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EMBRYO DONATION - PATIENT INFORMATION

1. What is embryo donation?

Embryo donation refers to the use of an embryo which has been donated from an individual or a couple who are called the "donors". Donor embryos arise when the person or couple have undergone treatment and wish to donate "surplus" embryos following the completion of their IVF journey. These embryos are used to assist single women, same sex couples, or heterosexual couples, known as 'recipients', in their attempt to become parents.

A donated embryo is used in a Frozen Embryo treatment cycle.

Embryo recipients have usually undergone IVF treatment themselves, and may have used donated sperm or oocytes in the past. Often their only option remaining is a donor embryo.

The decision to donate embryos or to receive donated embryos will have a significant impact on the donor, the recipients, and their families. Therefore donating or receiving donor embryos should be a carefully considered and informed decision encompassing legal rights and responsibilities of all parties including the potential child.

In Western Australia the donation and receiving of donor embryos is governed by legislation under the Reproductive Technology Act (1991) and the HRT Act Directions.

Information regarding donation can be discussed with the Donor Co-Ordinator or by emailing the clinic <u>info@pivet.com.au</u>.

2. Known vs Unknown Donation

PIVET can coordinate your treatment with the use of either a known embryo donor, or an unknown embryo donor, although the latter is the most common route.

- **Known donation** is when the identities of the donor and the recipient are known to both parties before the donation takes place. This could be between family members or friends, and may also be an acquaintance or recruited through advertising. The donated embryos are usually donated to and used by one recipient.
- **Unknown donation** is when the identities of the donor and the recipient are <u>not</u> known to either party before the donation takes place. The donors donate their embryos to the clinic and the embryos are then allocated to unknown recipients. In WA, up to five recipients can benefit from each unknown donation. This is considered the donors' five family limit.

To access PIVET's unknown donor embryo program, patients need to place their names on the donor waiting list. A consent to be on the wait list is signed at the patients initial appointment. The wait list works in chronological order and once patients near the top of the list, they will be contacted by the donor coordinator for the next steps in the process.

Once set up for a treatment cycle by a Clinician, recipients will be offered donor profiles from the donor coordinator. As the donors are unknown, only de-identifying information is provided on the profile. This includes; *height, build, hair colour, eye colour, complexion, blood group, age at donation, education, occupation, and ancestry.* The donor may also include their interests, their motivation to donate and a copy of their genetic reviews are included.

3. Who can be an embryo donor?

Couples or individuals who have completed their IVF treatment may choose to donate their remaining surplus frozen embryos. Embryo donors have usually completed their own families, and

may have different reasons for the desire to donate. They may have witnessed family members or friends struggle with infertility, they may have a personal experience of infertility and wish to help or they may prefer to donate their embryos rather than dispose of them.

The age of the egg provider at the time of embryo creation, the donors' medical histories as well as other factors such as the number and quality of the embryos are all considered before the clinic is able to accept the embryo donor.

Unknown donors must donate altruistically (not involving monetary compensation) and are only reimbursed for reasonable expenses. It is preferable for the egg provider of the donated embryos to be under the age of 36 years when the embryos were created.

4. What is involved in becoming an embryo donor? Processing, Screening & Quarantine

The couple or individual usually makes contact with the clinic once they have made a decision regarding the fate of their surplus embryos.

An appointment is made with a Fertility Specialist to explain the consenting and screening procedure prior to releasing the embryos for donation. The embryo donors are required to complete a Family Medical History Form detailing an extensive list of genetic conditions. They will also have a blood test and be required to provide a urine sample for testing for a number of diseases and conditions.

Screening Tests & Quarantine

Donated embryos are required to be 'quarantined' for a minimum of six (6) months. Many preliminary screening tests are carried out for patients embarking on IVF treatment, prior to their embryos being frozen. When the individual or couple decide to become donors these tests, along with some additional tests, are carried out. If the results satisfy quarantine requirements the embryos are then made available for use by recipients.

Blood tests are carried out for the following diseases and conditions:-

The tests include the following screens:

- Karyotype: all donors must have normal number and arrangements of chromosomes
- Cystic Fibrosis: 50 CFTR mutations that account for 85% of disease–causing CFTR mutations in the Australian population.
- SMA (Spinal Muscular Atrophy)
- Fragile X
- HIV I & II antibody
- HTLV I & II antibodies
- Syphilis
- Gonorrhoea
- Chlamydia
- Hepatitis B surface antigen
- Hepatitis B core antibody
- Hepatitis C antibody

Donors are screened for ethically related diseases, where appropriate:-

- Mediterranean or Asian heritage Thalassaemia
- African heritage Sickle-cell anaemia
- Jewish heritage Tay-Sachs and Gaucher's disease

NOTE:

Under West Australian Law, embryos may be stored for a maximum of 10 years, at which time storage period may be extended following application to the Reproductive Technology Council. The destiny of donated embryos following death of the donor(s), in the absence of clear direction from the donor(s), would be assessed on an individual basis.

5. Genetic Counselling & residual risks for donors & recipients

All embryo donors have an appointment with the Genetic Counsellor to discuss their Family Medical History form. A copy of their genetic consult is provided on the donor profile you receive as a recipient.

If a genetic disorder is declared by a donor, the recipient may wish to make an appointment with our Genetic Counsellor to discuss the risks of inheritance of this disorder in relation to the background general population risk.

Despite the level of screening performed, there are still risks associated with the treatment, as there are many other genetic diseases that are deemed to be at too low risk for testing or the technology is not yet available for testing. If pregnancy should result from the treatment, we cannot rule out the possibility of physical, mental or psychological abnormalities to the child from an unsuspected hereditary illness.

It should be noted that the risk of chromosomal abnormalities increases with the age of the donor, and that there are higher miscarriage rates and lower successful implantation rates in higher age groups for recipients.

All recipients are strongly encouraged to consult with PIVET's Genetic Counsellor, prior to a treatment cycle where donated embryos are being utilised.

6. Donor Implications Counselling

Counselling is provided by PIVET's Fertility Counsellor who has experience in all aspects of infertility and reproductive health issues. It is PIVET Policy that all embryo donors and all patients accessing unknown donor embryos have at least one counselling session to consider the implications for them and the donor conceived child. Follow up counselling can also be arranged if required.

Information regarding the medical, personal and social implications of caring for donor children is also available from:

- Reproductive Technology Council <u>http://www.rtc.org.au</u>
- Donor Conception Support Group http://www.dcsg.org.au

In the case of *known donation* all parties (donors, recipient & recipient partner if any) must attend two counseling sessions as individual couples and collective couples to commence and then to complete the required "cooling off" periods. The cooling off period is 3 months for embryos (HRT Act Directions 5.8 & Part 2 Schedule 4). During this time any person/party can decide to change their mind regarding the donation process.

7. Regulation and the law surrounding a child born from donor conception in Australia

The *Artificial Conception Act of 1985* protects the donor from any legal responsibilities or rights to any children born as a result of the donations, and any child born automatically becomes the legal child of the woman delivering or couple involved. This is the case for treatment of single women and couples (married, de facto, same sex).

In relation to a child born as a result of donation, all records are confidential to the clinic and the Reproductive Technology Unit Registers held by the WA Department of Health and identifying details are kept securely. The care of the child is the legal responsibility of the individual or the

couple who consent to the donation procedure, and the husband or partner (in a defacto situation), if any, is the legal father/parent of the child.

There is also a requirement that the recipient of donor gametes or embryos return to PIVET (or mutually agreed pathology lab) to have a pregnancy test performed following the completion of a donor (egg, sperm or embryo) treatment cycle. This is important as regulations require that PIVET, as well as the Reproductive Technology Registers held by the WA Health Department, keep track of all pregnancies from donor gametes or embryos.

Confidential identifying and non-identifying information about all donors, recipients, and children born as a result of donor treatment is supplied to the Reproductive Technology Unit Registers held by the WA Department of Health *http://www.rtc.org.au*. Under the Human Reproductive Technology Act (1991) Amendment 1, December 2004 any child born as a result of egg / sperm or embryo donation, on reaching the age of 16 years, will have access to identifying information about the donor, following approved counselling. This process may be facilitated by the Reproductive Technology Unit and clinics.

For children under the age of 16 years each donor and recipient needs to consent to sharing identifying information and the parent needs to consent on behalf of the child. There must be approved counselling of all parties (which may include the child).

All parties involved in donor conception (donors, parents of donor conceived children and donor conceived children over the age of 18 years), can register on the Donor and Offspring Register where they may be able to access identifying information. This depends on whether the other parties are also registered and their instructions on information to be made available. This register is managed by Jigsaw DNA Connect (<u>https://www.jigsawdna.org.au</u>).

8. Commonly asked questions & Extra Information

What is involved emotionally in choosing a donor?

Choosing a donor is one of the most challenging decisions you will ever make.

- Give yourself time to grieve your loss of a genetic connection to your child as the genetics of your child is determined by the donors genetics.
- Give yourself time to move forward and appreciate the options available through medical procedures.
- Take the time to realize that you (and your partner) are creating a child who is unique to your family and would not be created if not for your love for each other.
- Remember that blending the genetics of any two people will bring an unpredictable outcome in a child, a child that will be cherished regardless of hair colour or sporting achievement.
- Read about the characteristics of the donor and choose someone you can relate to and feel positive about. Choose someone who feels like a fit with your family.
- For couples it is important that the choice of donor is mutual.
- Make sure you are comfortable going ahead with treatment there is extra counseling available should you feel you need it.

What is involved in becoming a recipient of donor embryos?

Becoming a recipient of donor embryos involves attending a series of appointments with the IVF specialist, Counsellor and Donor Co-ordinator to understand the procedures and processes involved.

At the medical appointment, the recipient's medical history is reviewed, screening and hormone blood tests arranged, the process is explained and consent forms signed. Embryo recipients and their partners must have blood tests and any further genetic testing if required.

Recipients of donor embryos must meet with the clinic counsellor to discuss the implications of using donor embryos. This is an opportunity to consider all the issues and implications associated with the decision to be involved in the donor program and to make an informed decision.

The selection of a donor embryo (in the case of unknown donation) is made from a selection of embryo profiles that will be offered by the Embryo Donation Coordinator. Following the selection of a donor embryo profile, the recipient is allocated an embryo from their chosen donor.

A further meeting with the Fertility Specialist will follow to discuss the process and Frozen Embryo Transfer procedure.

Is there a waiting list to use donated embryos?

At PIVET there is a waiting list for people wishing to use donated embryos. Recipients are placed on the embryo waiting list after referral from their IVF Specialist.

The offering and allocation of donor embryos is managed on a "first come, first served" basis. When you reach the top of the waiting list the Embryo Donation Coordinator will contact you to initiate the process.

If the recipient is aged 45 or older there are further requirements that need to be completed before embryo profiles can be offered.

How many embryos will I be given?

One embryo is offered per cycle, and where possible a second embryo can be offered for a further attempt or sibling pregnancy. The number of embryos available from each donor can vary so a different donor may need to be selected for a subsequent treatment.

If a donor is selected and there is only one embryo available the Embryo Donation Coordinator will ask you to select another donor to be used as a back-up if required.

Sometimes more than one recipient (but no more than five) may benefit from each unknown donation depending on the numbers of embryos available.

I have chosen a donor profile, now what?

Once you have chosen a donor from the profiles supplied by the Embryo Donor Coordinator, the donor profile is signed to officially accept the donor for use in your own treatment.

All treatment cycle worksheets and associated consent forms are signed and verified by the donor coordinator with the donor code you have chosen.

You are now ready to be set up for your treatment.

What are the costs involved in receiving a donor embryo?

The cost of receiving an unknown donor embryo is not included in the frozen treatment cycle fee.

Please ensure that you arrange a meeting with the finance department so you are fully aware of the costs involved **prior to commencing a treatment** with the clinic.

What is the maximum time an embryo can remain stored?

Under West Australian Law, embryos may be stored for a maximum of 10 years, at which time it must be removed from storage and allowed to succumb.

When embryos are donated the storage period may be extended following application to the Reproductive Technology Council.

Can embryo donors be paid for their donations?

No, donating embryos is purely altruistic. In Australia it is illegal to receive or make any payment for human tissue, including donated embryos. Under the NHMRC Guidelines, embryo donors may be reimbursed for reasonable, verifiable expenses incurred during the donation process, such as travel and parking, however they cannot be compensated for loss of work time.

Can I request transport or transfer of a donor embryo to another clinic to continue treatment?

In unknown donation, the donor material has been donated to PIVET for use within the clinic, therefore the recipients treatment using unknown donor embryos is to be carried out at PIVET.

If the donor embryo is from a known donation, then the transfer to another clinic in Australia can be facilitated. This is done by the recipient making contact with their chosen Fertility Clinic and informing them of the intended transfer. PIVET will need to be notified at the same time so release forms can be arranged and signed. The laboratory at PIVET will then liaise directly with the receiving clinic to organise the transfer.

The costs of transporting embryos to another clinic are paid by the recipient. Please speak to the finance department so you are fully aware of the costs involved in embryo transport.

What are the legal requirements for transportation of donor embryos outside Australia?

Transfer of donor embryos to an overseas clinic requires providing additional information to the receiving clinic. This may include information about the Laboratory process, screening for infectious diseases and the standards of quarantine.

PIVET cannot export donor embryos for use in a commercial surrogacy arrangement overseas as commercial surrogacy (where payment is given to the surrogate) is illegal in Western Australia.

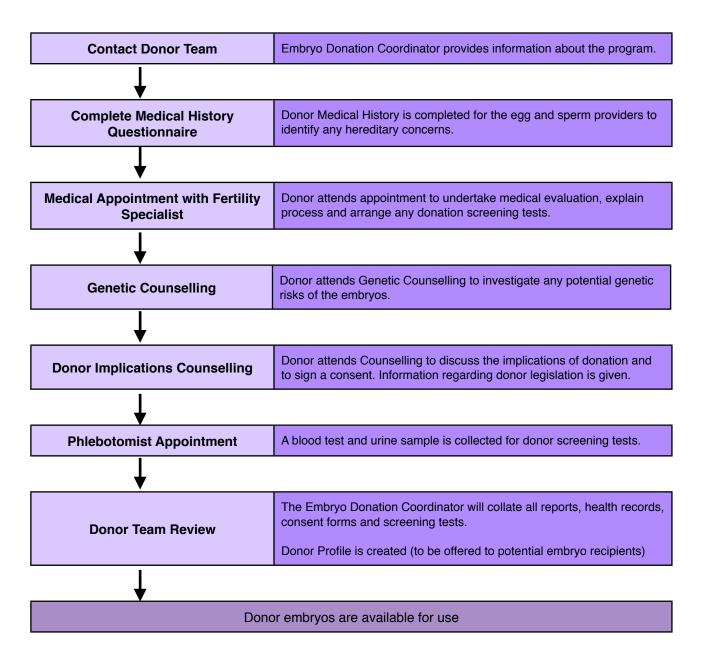
The clinic must seek approval from the RTC for the export of donor embryos. Conditions for RTC approval may include:

- Provision of information about the use and outcome of the donation.
- Provision of donor-identifying information.
- Compliance to the 5 family limit (i.e. only 5 families can be created for any one donor) for the donors.
- Effective Consent which includes the awareness of legal requirements, and the rights and responsibilities of donors and the recipients.
- Application for a birth certificate and Australian requirements for registration of a birth need to be clarified for any child born from donation.

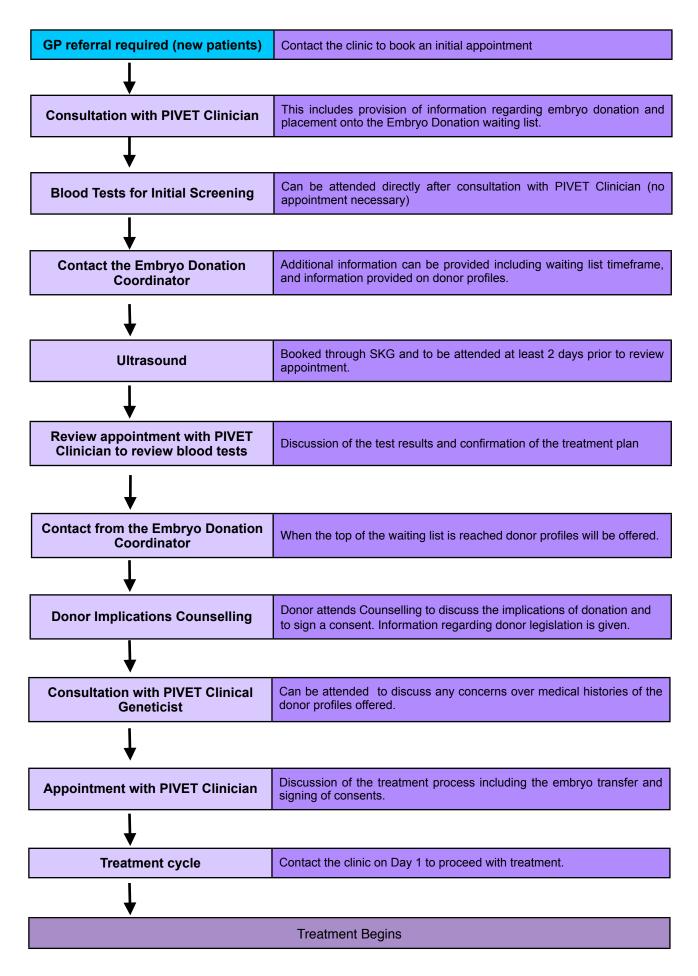
The clinic receiving the embryos must submit a written undertaking to provide the necessary information to PIVET and to the Reproductive Technology Council.

Donor embryos cannot be exported until all the information is obtained from the receiving clinic in relation to the above requirements.

Embryo Donation (Donor)



Embryo Donation (Recipient)



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9. References

WA Reproductive Technology Council

www.rtc.org.au

Information about relevant WA legislation, including the Donor Register and access to identifying information for donor conceived persons.

Victorian Assisted Reproductive Treatment Authority

www.varta.org.au

Victoria's legislation is different to WA's, however, this website provides some very useful resources, including the publications: *Why, when, and how to tell children about donor conception*; Kirkman, M. et al. *Telling It Your Way: A Guide for Parents of Donor Conceived Adolescents,* and the webinar *"Time to Tell"*.

Donor Conception Support Group

www.dcsg.org.au

Australia wide internet-based support group for donors, recipients, and offspring; has various publications available for purchase and identifies other activities and resources.

Rainbow Families

www.rainbowfamilies.com.au

Internet based support group for same-sex couples/parents, mainly based on the East Coast. Variety of activities, resources, and special interest groups etc.

Solo Mothers by Choice

www.smcaustralia.org.au

Internet based support group; based on the USA group, *Single Mothers by Choice*. State-based activities/social meetings.

Assisted Reproductive Technology: Books for Children

http://booksfordonoroffspring.blogspot.com

Lists and reviews a wide range of books for parents and children which explain assisted reproduction, includes IVF, egg /sperm and embryo donation, surrogacy, adoption, gay/single and heterosexual parents, and includes books in languages other than English. Updated regularly.