

CONCEPT FERTILITY DONOR PROGRAM



Recipient of Unknown Donor Sperm
Information Booklet

Welcome

to the Concept Fertility Donor Program and thank you for allowing us to help guide you through your fertility journey. This booklet contains information regarding each step of the process of becoming a recipient of an unknown sperm donor. Please read through the information carefully and direct any questions you may have to the Donor Coordinator at donor@conceptfertility.com.au. We look forward to helping you find the right match.

Step One: GP Referral

The first step is to see your General Practitioner (GP) and request a referral to see one of our fertility specialists. A GP referral is a requirement to ensure that you are eligible for a Medicare rebate. A GP referral is valid for 12 months.

Step Two: Choose a Specialist

We have five specialists with referring rights to the Concept Fertility Donor Program. Please select from the links below to learn more about each doctor and how to make an appointment. Please note that Dr Adam Gubbay offers intrauterine insemination and cycle tracking only.



[Dr Lucy Williams](#)



[Dr Kevin Artley](#)



[Dr Graeme Thompson](#)



[Dr Mini Zachariah](#)



[Dr Adam Gubbay](#)

Some of our specialists will only see patients with private health insurance. Please note that your insurance cover must include assisted reproductive services to be eligible. Pregnancy extras does not provide adequate cover. Please see below before you call to book an appointment:

Specialist	Private Health Insurance Required?	
	Yes	No
Dr Lucy Williams		✓
Dr Kevin Artley		✓
Dr Graeme Thompson	✓	
Dr Mini Zachariah	✓	
Dr Adam Gubbay	✓	

During your appointment, your doctor will complete a *Recipient Donor Allocation Form*, which will prompt one of our Donor Coordinator's to contact you for the next step.

Step Three: First Counselling Appointment

Once the *Recipient Donor Allocation Form* has been received by the Donor Coordinator, they will contact you to book your first counselling appointment. **It may take up to a week for the Donor Coordinator to receive the Allocation Form from your Doctor.** The purpose of the first counselling session is to discuss the implications of receiving donor material and assist in preparing you for the future as a parent of a donor-conceived child. The counsellors, at their own discretion, may request further preliminary counselling or request to involve other parties when they are introduced during your session prior to your inclusion on the waitlist.

The counselling report will be forwarded to the Donor Coordinator to indicate that all preliminary counselling has taken place. The Donor Coordinator will then contact you and advise that you have been placed on the waiting list. **It may take up to a week for the Donor Coordinator to receive the Counselling Report.** If more than a week has passed and you have not been contacted by a Donor Coordinator, please get in touch with us at your earliest convenience.

Step Four: The Waiting List

For new patients, the date that you see the counsellor becomes your waiting list date; however, for recipients that have moved from other clinics and previously completed their counselling, then the date that they see their Concept Fertility Specialist for the first time will become their waiting list date. The waiting list date will be used to indicate where you appear on the waiting list.

Leaving the Waiting List

If you do wish to leave the waitlist for any reason prior to viewing donors, please let the Donor Team know. This ensures that you will not be contacted unnecessarily once you reach the top of the list. Your position on the waiting list will simply be inactivated, which means that you can be re-activated at any time in the future without losing your position.

Wait Times

Unfortunately, we cannot provide a precise timeframe for you to reach the top of the waiting list, as there are too many variables involved to be able to provide you with an accurate answer. We can make a broad estimation, such as six, twelve or eighteen months, but this can be subject to change. Our key variables are: supply, sperm quality, and ethnicity choice.

Supply

The supply of available donors is unpredictable and can lead to greater than expected wait times. We employ many initiatives to recruit new donors and also seek to release donors that have not been utilised by recipients within certain timeframes. This will be discussed in further detail under our [Fair Use policy](#).

Quality

Donors may not have appropriate sperm quality to match the treatment type prescribed by your Specialist. You can read more about this under [Sperm Quality](#).

Ethnicity Choice

We accept donors from a multitude of ethnic backgrounds. We ask our recipients to advise us of their ethnicity choice(s) when they join the waitlist, but this is no guarantee that we will have a donor match. Should a recipient choose an ethnicity that is in low demand, the recipient will be offered donor profile(s) to view regardless of their waiting list date, which will decrease their wait time. Therefore, to ensure that recipients choose their ethnicity or ethnicities based on true desire and not time factors, the Donor Coordinators will not disclose the donor ethnicity types within the current donor pool unless the recipient is at the top of the waiting list.

When donor supply is low and no ethnicity match is possible, those at the top of the waiting list will be asked if they wish to view the profile(s) of donors from outside their ethnicity choice. This is a courtesy to allow our recipients every opportunity to find a suitable donor. We ask that you please indicate if you would prefer not to be offered the option to view any donor outside your ethnicity choice(s) when the Donor Coordinator requests your preferences.

Waiting recipients are welcome to contact the Donor Coordinators via email to discuss if their given timeframe is still valid, but it is requested that this occurs not more than once every four to six months, as this can quickly become resource intensive and greatly slow the process as a result.

Step Five: Viewing Donors

Once at the top of the waiting list, the Donor Coordinator will email you donor profiles to view. We believe that the most important person in this process should be responsible for filtering through the donor characteristics, and that's you. There is therefore no maximum number of donor profiles that you will be offered for you to view, as **you will be offered all donors available that meet your sperm quality needs and ethnicity choice(s).**

The profiles feature all of the non-identifying characteristics and medical history of the donor and their family. To ensure the safety of all donations, Concept has a strict screening policy which covers both infectious diseases and genetic carrier screening. Please see [Donor Genetic Screening](#) to learn more about why we test for genetic conditions and the processes related to testing outcomes.

Timeframe

Each recipient has a **maximum of one (1) week** to select their donor from the profiles provided. We regret that we do have to strictly abide by this one week viewing period as we must keep this as fair and equitable for our recipients as possible. If none of the donors are suitable, then they will return to our donor pool. You will then re-join the top of the waiting list until more donors can be found for you.

If the Donor Coordinator does not receive a reply with your selection within the one week timeframe, it will be assumed that no donors were suitable and they will be returned to the donor pool for the next recipient to view. It is therefore vital that the viewing time is adhered to in order to avoid disappointment. We are unable to extend the viewing period for any recipient nor allow you to “hold” a donor until more donors become available, as this will detrimentally impact other waiting recipients.

Step Six: Donor Selection

Along with the provided donor profiles received for viewing, the Donor Coordinator will also attach the *Recipient Selection and Declaration Form*. Completing, signing and returning this form to the Donor Coordinator will secure your choice of donor. This form is offered as an electronic PDF, so it can be completed and signed electronically if you choose to do so. **Please ensure that this form is returned prior to the end of the one week viewing period.** The *Recipient Selection and Declaration Form* also lists the responsibilities that you have as a recipient of donor sperm to continue liaising with the Donor Coordinator. **This is very important and remains relevant throughout your treatment.** Please see [Donor Coordinator Liaison](#) for further information.

Fair Use Policy

The Concept Donor Sperm Fair Use policy states that **all donor sperm recipients that have not used their donor for a period of greater than six months will automatically relinquish their right to the use of that donor.**

This policy primarily seeks to identify those that may have had a change of heart, mind, relationship or situation which has led to them no longer needing a donor. It is not uncommon for this to occur without our awareness. Those that still wish to use their donor and need more time need only ask and a new date may be negotiated. If the requested extension is significant, it may be suggested that the recipient return to the top of the waitlist until they are ready to proceed.

Step Seven: Second Counselling Appointment

The purpose of the second counselling session is to revisit all donor recipient implications now that you have chosen a donor. As it may have been a while since your first session, this second session ensures that you feel psychologically prepared to continue on your journey now that a donor has been selected and treatment approaches.

Step Eight: Specialist Appointment

Once a donor has been chosen and you have seen the counsellor, you will need to make another appointment with your specialist in order for treatment orders to be written. Treatment orders indicate the type of treatment that you require, the medications you will need (if any), and grants the Concept Nurse Coordination Team responsibility to act as the liaison between you and your specialist during treatment. These treatment orders are sent to the Nurse Coordinators in preparation of your treatment phase.

Step Nine: Nurse Coordinator Appointment

Once you have seen your specialist and they have written your treatment orders, you will need to make an appointment to see a Nurse Coordinator. **This will begin your treatment phase.** The Nurse Coordinator will discuss the treatment and medications prescribed by your doctor; provide the relevant consent forms; and facilitate the remainder of your fertility journey in conjunction with the Nurse Coordination Team and your specialist.

Your Responsibilities: Donor Coordinator Liaison

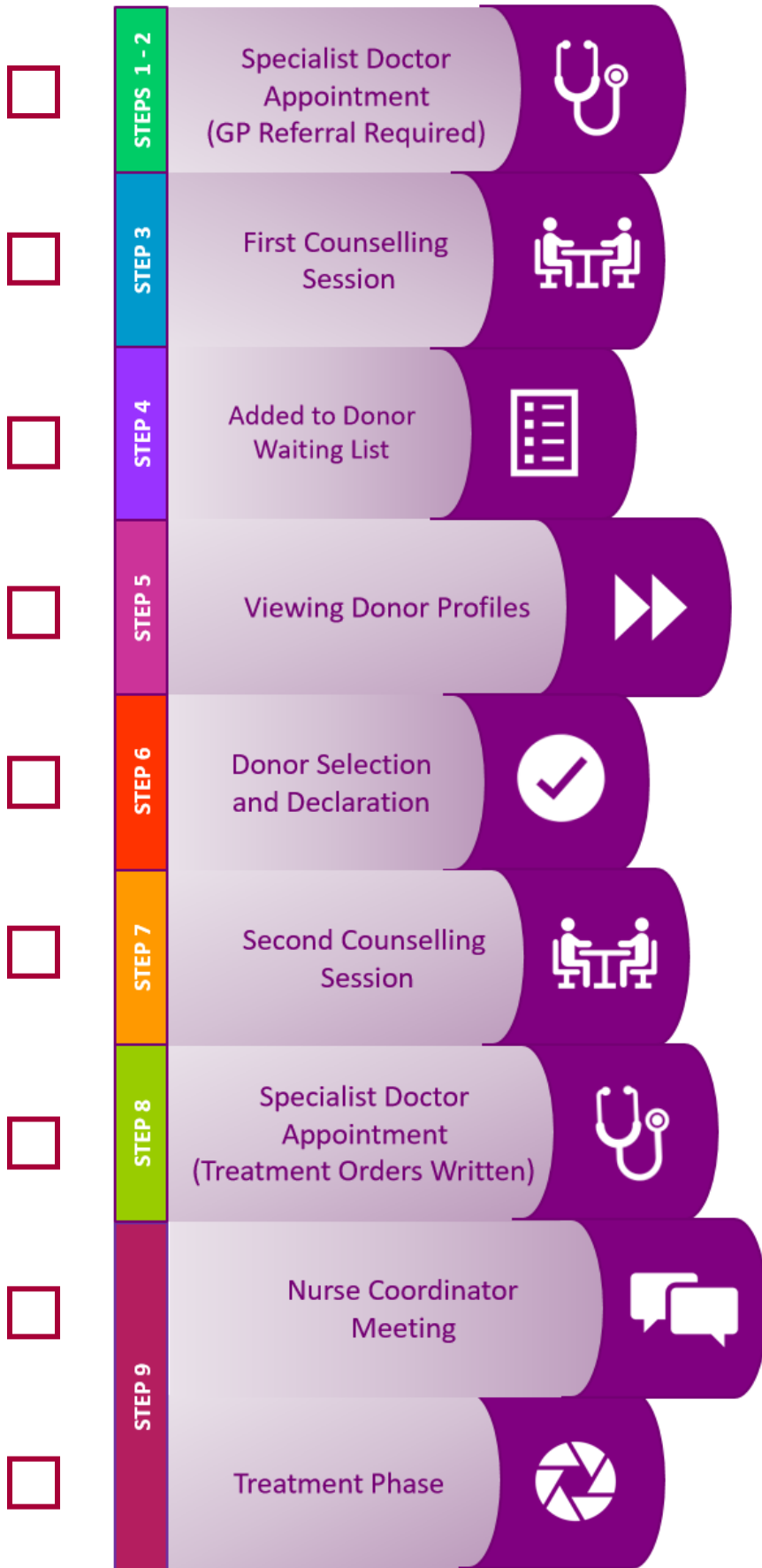
Once you enter the treatment phase, the Donor Coordinator is no longer privy to your activities, as the Nurse Coordinators have now assumed responsibility for your ongoing care. **The obligation to advise the Donor Coordinator of the following circumstances now rests with you:**

1. After completion of three (3) cycles using your donor
2. When you are no longer using your donor, e.g. family is completed
3. If your treatment type changes from IUI to IVF/ICSI If your family circumstances change, i.e. separation, partnership, etc.

Continued **liaison with the Donor Coordinator is vital** in ensuring that your donor remains a viable option for your treatment and that all legislative requirements for the use of your donor continue to be met.



RECIPIENT PROCESS AND CHECKLIST



Notes

Sperm Quality

The term “quality” can be a very confusing term when considered in the context of sperm, as although the sperm is referred to in terms of quality, the true meaning actually relates more accurately to “sperm number”. All of our donor sperm on offer is of the highest quality, so when you hear, for example “this donor has ICSI quality sperm only”, what is really being said is, “this donor’s sperm number is such that it can only be used for an ICSI procedure in order to best achieve a pregnancy”.

Here is a more in-depth overview of the sperm quality (number) required for each type of procedure:

Intrauterine Insemination (IUI)

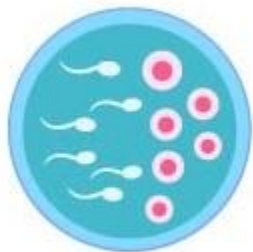
This procedure involves inserting a catheter into the uterus through the cervix. The sperm then travels from the uterus to the egg for the purposes of fertilisation. We therefore require a large number of sperm to increase the chance of them successfully reaching the egg.

Sperm Quality Required:

Greater than 5 million sperm per mL

IVF (In Vitro Fertilisation)

With IVF, the eggs that require fertilisation have been taken from the body and placed in a small dish within the laboratory environment. For this procedure, the embryologists add sperm to the same dish for the purposes of fertilisation. As the sperm do not have as far to travel as with IUI procedures, not as much sperm is required to achieve success.



Sperm Quality Required:

Greater than 2 million per mL, but less than 5 million per mL

Intracytoplasmic Injection - ICSI

This procedure is much the same as IVF in that the eggs have been taken from the body to be fertilised. It is the manner in which we attempt to achieve fertilisation that differs. With ICSI, the embryologist selects a single sperm for each individual egg and manually inserts the sperm into the egg using a microscopic needle. As very little sperm is required to be able to provide one sperm for each egg, low sperm numbers are suitable to successfully perform this procedure.



Sperm Quality Required:

Less than 2 million sperm per mL

This is why being aware of the sperm quality required for your treatment is so important. Whereas IUI quality sperm could

be used for any of the above procedures, IVF quality sperm could only be used for IVF or ICSI procedures, and ICSI quality sperm could only be used for ICSI procedures. Our recipients are therefore separated into the categories of IUI and IVF/ICSI on the donor waiting list to ensure that the appropriate sperm quality is provided.

IVF vs ICSI

Some of our donors have IVF quality sperm and some have only ICSI quality sperm. If you are categorised by your doctor as requiring an egg retrieval, you will be categorised as requiring IVF/ICSI sperm and your donor may have IVF or ICSI (or both) quality sperm available. You will be offered donors from both of these categories. The quality at the time of choosing is not defined. When you see your specialist for treatment orders after choosing your donor, your treatment orders will reflect the type of procedure needed based on the sperm quality of the donor.

Please note that the decision between conducting an IVF or ICSI procedure can still be changed on the day of your procedure, as sperm thawing does not always guarantee the expected outcome. **Your embryologist will make the best decision on the day to guarantee that your eggs have the best possible chance of fertilisation.** For example, your donor has IVF quality sperm; however, the thaw of the sperm sample has resulted in lower sperm numbers than expected and is now only suitable for ICSI.

Donor Genetic Screening

What Genetic Diseases Are Donors Screened For?

Concept utilises the InVitaE pre-conception carrier screening test for four common genetic disorders. The test will identify if the donor is a carrier of:

- Cystic Fibrosis (CF)
- Spinal Muscular Atrophy (SMA)
- Fragile X Syndrome (FXS)
- Thalassaemia Trait

Why Test For These Conditions?

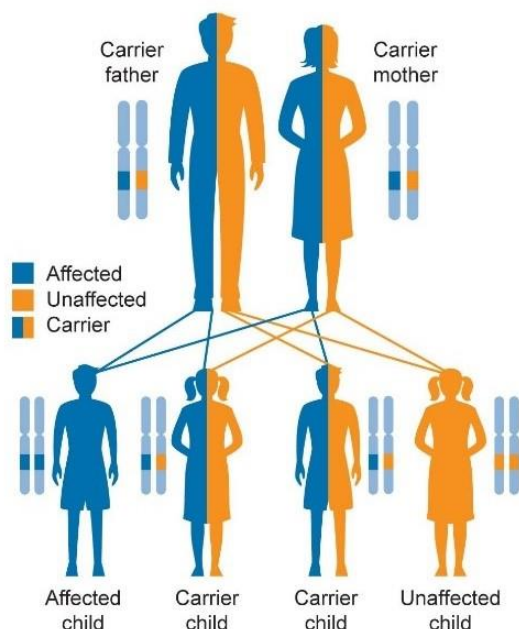
CF, SMA, FXS and Thalassaemia Trait are among the most commonly inherited genetic conditions. Please see in more detail below:

- CF is the most common life-limiting genetic condition in Australia.
- SMA is the most common genetic cause of death in children under the age of two.
- FXS is the most common form of inherited intellectual disability.
- Thalassaemia is an inherited blood disorder characterised by less oxygen-carrying protein (haemoglobin) and fewer red blood cells in the body than normal.

Carriers of these disorders are often unaware of their status and often do not have a history of these conditions in their family. Although these conditions do not have a cure, early treatment and supportive care may improve quality of life.

What Does Being A Carrier Mean?

A carrier is a person who has a faulty gene in their DNA, but in most cases does not have any associated health problems. Carriers are; however, able to pass that faulty gene onto their children, who may then develop a genetic disorder. CF, SMA and Thalassaemia are



known as recessive disorders, which means that *both parents* must pass on the faulty gene for their children to be affected. A couple who are both carriers for the same disorder have a 25% risk of having a child that will be affected by that disorder. 50% of children will be carriers of the faulty gene and 25% will be unaffected. In Australia around 1 in 25 people are CF carriers and 1 in 40 are carriers of a faulty SMA gene.

The risk of a child being born with CF in Australia is around

1 in 3000 births and for SMA it is estimated to be between 1 in 6000 and 1 in 10,000 births.

FXS is an X-linked disorder which means that the faulty gene is found on the X chromosome. Female carriers of FXS have a 50% risk of passing on the faulty gene to their children, who in turn may develop FXS. The risk of being a FXS carrier is 1 in 250 and there is a 1 in 4000 risk of a child being born with fragile X mutation.

What Happens If a Donor is a Carrier?

If a donor is a carrier of a CF, SMA, or a Thalassaemia faulty gene then the recipient will be required to undergo screening before using the donor. If the recipient does not have the faulty gene then the risk of having an affected child is low. If the anonymous donor is carrier of Fragile X, we will be unable to accept this donation. For known donors who test positive for Fragile X, genetic counselling will be required before proceeding. This cost will be covered by the participants.

The recipients of unknown donors will receive complimentary screening, whereas recipients of known donors will incur the screening fees.

Recipients choosing a donor who is a carrier must undergo Genetic Counselling before starting the program. For recipients using unknown donors this service is provided at no cost. For those with a known donor, Genetic Counselling fees will be borne by the recipient.

What If The Donor Tests Negative?

Even if the donor is negative for the genes screened there is always a slight risk that a donor could still be a carrier. A negative carrier test result reduces the risk but does not completely eliminate the chance that the donor may be a carrier. The risk that a donor could still be a carrier after a negative test result is termed a *residual risk*.

The table below provided by InVitaе shows the theoretical residual risk after an individual tests negative. These values are based on the detection rate for the condition at InVitaе, and assumes that there is no family history or symptoms. It can be seen that residual risk can vary based on the ethnic background of the donor. Please note that the below values are a guide only.

CONDITION	ETHNICITY	CARRIER FREQUENCY BEFORE SCREENING	CARRIER RESIDUAL RISK AFTER NEGATIVE RESULT
CF	Caucasian	1 in 28	1 in 2700
	Asian	1 in 88	1 in 8700
SMA	Caucasian	1 in 45	1 in 880
	Asian	1 in 50	1 in 701
FXS	Caucasian	1 in 187	1 in 18,600
	Asian	≤ 1 in 500	Reduced
THALASSAEMIA	Caucasian	≤ 1 in 500	Reduced
	Asian	1 in 20	1 in 191