



Preparing to access non-identifying information about your donor and donor-conceived genetic sibling(s)

This leaflet has been produced by the Human Fertilisation and Embryology Authority (HFEA) for donor-conceived people who:

- are aged 16 or above, and
- were conceived through treatment at a UK-licensed clinic after 1 August 1991

who want to:

- apply for non-identifying information about their donor and/or other people conceived with the same donor (donor-conceived genetic siblings)
- find out if their donor has agreed to share their identity with people conceived from their donation once they are 18.

You may have known for some time that you were conceived with the use of donated eggs, sperm or embryos, you may have only just found out, or, you may only suspect this to be the case. If you are aged 16 or over, you are entitled to apply to us to find out more.

If we hold information about your parent(s)'s fertility treatment which resulted in your birth on our secure database ('the Register'), we can give you any non-identifying information we hold about your donor(s). Details of what this could include can be found on our website at www.hfea.gov.uk/112.html, though it is often quite limited.

We can also tell you the number, sex and year of birth of any other people conceived with the help of that same donor (donor-conceived genetic siblings).

The process of accessing information (known as 'Opening the Register') can raise unexpected feelings, so before you decide whether to apply it's important to think about what effect this could have on you and your family. This leaflet outlines some of the things you might want to consider before going ahead.

We strongly encourage you to take advantage of our confidential support service which gives you the chance to talk things through with a donor conception support worker in a way and at a time to suit you – this could be by phone, email or in a face-to-face meeting.

For most people this service is free – contact details to access this service are at the end of this leaflet under 'find out more'.

Some things to think about

In the past egg, sperm and embryo donation was anonymous and donors would only provide non-identifying information about themselves to be shared. However, the law changed in 2005 to allow

past donors the opportunity to 'become identifiable', which means they re-register with us and agree to their identity also being shared with people conceived from their donation (once they are 18).

Only a small number of donors have re-registered to become identifiable but we can tell you if yours is one of these. If they are, you can apply for identifying information about them from the age of 18 if you wish.

If you are over the age of 18, it's also possible that one or more of your donor-conceived genetic siblings (if there are any) may have agreed to share their name and contact details with you (through a service called Donor Sibling Link). If you discover you have any donor-conceived genetic siblings, you will be provided with information about this service.

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If you decide to go ahead and ask us for information about your donor or donor-conceived genetic siblings, you're likely to go through many different emotions: anxiety, curiosity and excitement may all play a part.

Your feelings may change and perhaps become more intense after you have received the information. You may change your mind about what to do more than once, or go so far and then stop and maybe return to it in the future. This is understandable and quite normal.

Think carefully before sharing any information about this process or details about your donor with people on social media sites such as Facebook and Twitter – once shared it's out of your control.

Things to consider

Is this a good time in your life to get information about your donor?

Where you are in your life at the moment may affect how well you can cope with the possible feelings you will have, especially if you have recently been through a major life event such as a relationship breakdown, birth, or death.

What else is going on for you? What are your reasons for wanting information at this particular time?

Who do you have to support you?

Who else knows about your application and how supportive are they?

Are any of your siblings also donor-conceived?

If so:

- Do you share the same donor?
- Are they too young to access the information themselves? Will you pass it on to them?
- If you've told them, how do they feel about you applying for this information?
- What impact could this have on them and on your relationships with them and with your family as a whole?

Have you told your parents or other family members?

Including your family in this process and being as open and honest as possible may help them and you feel more at ease.

However, some family members may prefer you not to go ahead. Will this make a difference to your decision? How will you handle it either way?

What do you expect to find out from us?

Wherever possible, we will give out the information we hold in the donor's own handwriting. The quality and quantity of the information can vary a lot and could be very disappointing.

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Your donor(s), at the time they donated, might not have realised that you would be told or find out you're donor-conceived, or may not have realised the importance to some donor-conceived people of having good quality information about their donor. Some donors have not provided any biographical information.

What if your donor seems totally different to you?

You may not have anticipated your donor's lifestyle and circumstances and they may not have anticipated yours. For example, you may not have considered each other's sexual orientation or family set up (eg, single parent or divorced/separated family).

You may not share the same social/educational/cultural background, you could have very different life experiences and lifestyles, and your first language may not be the same.

Have you got any expectations about how many donor-conceived genetic siblings you may have?

Up to 10 different sets of parents can use the same donor and each can use the same donor for more than one child. So it's possible you may have more than 20 donor-conceived genetic siblings; but it's also possible that you have none.

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Remember that the donor may also have had children of their own at the time they donated or may have subsequently had children.

We can only tell you about any children the donor had at the time they donated, if this information was provided.

If you are over 18 and you discover that there are others conceived with the help of the same donor, you will be eligible to join Donor Sibling Link. This is a voluntary contact register for adult donor-conceived individuals who wish to exchange contact details with their donor-conceived genetic siblings (further information is below under 'find out more').

Will I ever be able to find my donor?

If your parent(s) used an anonymous donor(s), there's a small chance that the donor has since chosen to remove their anonymity (re-registered as identifiable).

If this is the case, and you are aged 18 or over, we would be able to provide you with identifying information about them (including their full name, date and place of birth and most recent address held on our database (called the Register)). This information can help you make contact with your donor should you wish to.

You should consider what you would do/how you would feel if you discovered your donor has re-registered as identifiable, or if they remained anonymous.

If your donor hasn't re-registered as identifiable, you may feel frustrated as you may have strong feelings about wanting to find them.

However, as you will only be able to obtain non-identifying information about them from us, it's unlikely that this information could lead to you being able to trace them.

Find out more

You can find out how to apply for information about your donor on our website – www.hfea.gov.uk/113.html – or by calling us on 020 7291 8200.

If you plan to enter into an intimate relationship with someone who is also donor-conceived, we can also tell you if you are related to them. You must apply jointly to us for this information.

More information about obtaining information about your donor-conceived genetic siblings through Donor Sibling Link is available at www.hfea.gov.uk/donor-sibling-link.html or by calling us on the same number.

We strongly recommend that you talk to a professional about the implications of obtaining information about your donor and donor-conceived genetic siblings. Please contact us at openingtheregister@hfea.gov.uk or on 020 7291 8200 for details of how to access our independent and confidential specialist support and intermediary service.

If you're worried about the lack of information you have about your donor's personal and family medical history, the leaflet 'Finding out about your donor's personal and family medical history', produced by a campaign called Lifecycle, may be of help. You can access it on our [website at www.hfea.gov.uk/lifecycle.html](http://www.hfea.gov.uk/lifecycle.html).

Other useful contacts

Donor Conception Network

An organisation supporting donor conception families: www.dcnetwork.org.

Counselling:

British Infertility Counselling Association – a professional association for infertility counselling: www.bica.org.

British Association for Counselling and Psychotherapy – a directory of registered counsellors: www.itsgoodtotalk.org.uk.

Counselling Directory – a database of UK counsellors and psychotherapists: www.counselling-directory.org.uk.

Ask for counsellors specialising in the area of donor conception.

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Version 2

Originally published in April 2015, revised
September 2016

Review date: September 2017

Did you find this leaflet useful? Could it be improved? Please let us know by emailing enquiristeam@hfea.gov.uk. You can also email us if you'd like to know more about our evidence sources.