

UK DonorLink

UK Voluntary Information Exchange and Contact
Register Following Donor Conception Pre 1991



Donor Conception **FIND THE MISSING PIECE...**

Are you a donor-conceived adult?

Would you like more information about your donor?

Are you a donor?

Have you donated sperm, eggs or embryos and would you be willing to update your information for those conceived from your donation?

...BRINGING THE PIECES TOGETHER

For more information:

Visit our website www.ukdonorlink.org.uk

Contact us for confidential advice

or to receive our leaflet on 0113 278 3217

or e-mail: info@ukdonorlink.org.uk

**"UK DonorLink Voluntary Information Exchange and Contact Register seeks to provide a balanced service whereby rights to information are balanced with rights to privacy."
Marilyn Crawshaw, Chair of UK DonorLink Advisory Group**

- Were you born as a result of a donation of sperm, eggs or embryos?
- If so, would you like to find out about the person who donated the sperm, eggs or embryos?
- Would you like to know if you have half or full siblings to whom you are genetically related?
- Have you donated sperm, eggs or embryos in the past? Would you like to provide updated information about yourself that could be passed on to anyone born from that donation?

The 'UK DonorLink Voluntary Information Exchange and Contact Register Following Donor-Conception pre 1991', provides an opportunity for donor-conceived adults, their genetically related siblings and donors to exchange either identifying or non-identifying information with each other.

What is UK DonorLink?

Today we know that many people directly affected by donor conception would like the opportunity to find out more about those to whom they are genetically related through donation.

As a result of a Department of Health grant made in April 2003, UK DonorLink has been established by After Adoption Yorkshire, an agency already experienced in the field of post-adoption support.

The register provides a service for donor-conceived adults who want to obtain more information about their genetic origins. It is also for those donors who wish to know if anyone has been conceived with the assistance of their donation and are willing to provide information to those who join the register. Donor-conceived adults may also want to be linked with, or to have information about, their genetically related half or full siblings.

Who can join UK DonorLink Voluntary Information Exchange and Contact Register?

Joining the register is voluntary.

It is open to:

- Donor-conceived adults aged 18 years and over
- Donors of sperm, eggs or embryos
- Genetically related half or full siblings aged 18 years and over



"Not knowing anything about 50% of my genetic make-up is disturbing. I want to know about my hereditary health and about the man who was partly responsible for my existence, so that I have a sense of where I come from. It's deeply unsettling to have to live with such a significant missing piece."

Sarah, Donor-Conceived Adult

How will the Voluntary Information Exchange and Contact Register work?

If you are a donor-conceived adult, donor, or a genetically related half or full sibling, and you want to consider registering, then you will be invited to discuss this with us before completing a registration form. Information from the completed registration form will be held on a secure UK DonorLink database.

You will also be offered the opportunity to discuss the implications of registration with a UK DonorLink counsellor. There will be no charge for this service and it will be in confidence.

UK DonorLink will offer you the option of undergoing a DNA test. The reason for this is that it is difficult to establish whether people are genetically related except through DNA matching. You may choose to undertake a DNA test either at the point of registration or when a possible match has been identified.

The DNA test will be organised through UK DonorLink. Although there will be no cost for registration onto the register itself, there will be a charge for the DNA test, which will be kept as low as possible. Assistance may be available in cases of financial hardship. A detailed information sheet is available about the DNA process.

Your DNA profile will be placed on a confidential and secure UK DonorLink DNA database and will be checked for possible genetic matches with other registrants' DNA profiles on the database.

This DNA database will be held on behalf of UK DonorLink by a specialist agency that is experienced in the secure storage of DNA samples. This UK DonorLink DNA database will only be used for the exclusive purpose of matching donor-conceived adults, donors and genetically related half or full siblings.



How to join the Voluntary Information Exchange and Contact Register?

Contact UK DonorLink, 31 Moor Road, Headingley, Leeds LS6 4BG
or telephone 0113 278 3217, email: info@ukdonorlink.org.uk
or register an interest on line www.ukdonorlink.org.uk

If you wish to join the register, you will need to complete a registration form which contains personal details and information about your donation or conception, if known. Information is only entered onto the register once a signed registration form is completed. Registration forms can be obtained either directly from UK DonorLink by post or on line. Sample copies can be viewed by logging onto the website at www.ukdonorlink.org.uk. Proof of your identity will be required prior to registration.

It is important that UK DonorLink is kept fully informed of any subsequent changes of name or address.

What information will be made available following a match?

When joining the register you may specify your wishes about contact at this stage. For example, if you think that you will want information to be exchanged with anyone you are matched to but will not want any direct contact, then this can be noted. Instructions can be varied by yourself at any time by contacting our staff.

If a match is made on the UK DonorLink DNA database, you and those involved will be contacted at this stage by UK DonorLink staff, so that the way forward can be mutually agreed. Identifying and/or

non-identifying information can only be exchanged with the consent of both parties.

What is identifying information?

This is any information that identifies or has the potential to identify a person. This information will only be released when the consent of the person about whom the information relates to has been obtained in writing.

What is non-identifying information?

This provides details about a person but does not identify him or her. This may include a physical description, family background, education, occupation, medical details and personal interests. This information will only be released when the consent of the person about whom the information relates to has been obtained in writing.

Both identifying and non-identifying information can only be exchanged with the written consent of yourself and the parties concerned. These are:

- Donor-conceived adults aged 18 years and over
- Donors of sperm, eggs or embryos
- Genetically related half or full siblings aged 18 years and over

"I would hate for anyone conceived through my donation to wonder who I am or what I look like and not to be able to find out."

John, Donor

What happens if a match is made?

If you and another party have been matched following your registration with UK DonorLink, you will both be notified in writing. You will both be asked to state your wishes about the exchange of identifying and/or non-identifying information and about making direct contact, if that is being requested. Both parties in the match will be asked to complete a form at this stage (if they have not already done so), giving non-identifying information about themselves that will be passed on to the other party. If both parties have given written consent for identifying information to be passed on as well, then this information will also be released.

If you state in writing that you do not want any direct contact with another registered person then this will be honoured and the other matched person will be notified of this.

It is strongly recommended that you should discuss your decision and its implications with a UK DonorLink counsellor before any information is released.

What help and support is provided?

UK DonorLink encourages all those thinking of placing their name on the register to talk through the implications with us. We can either arrange to meet with you at our office or put you in touch with a UK DonorLink approved counsellor in your area. There is no charge for this service.

Following a match, UK DonorLink will manage the exchange of information process. We will also act as intermediaries in any direct contact, if that is requested by you.

What about those conceived by donor conception and donors post 1991?

If you would like information about any donations that were made after 1991, then you should contact the Human Fertilisation and Embryology Authority (HFEA) for help and advice.

21 Bloomsbury Street,
London,
WC1B 3HF.
Tel: 020 7291 8200
e-mail: admin@hfea.gov.uk

Feedback from users of the register is always welcomed.

If you wish to inform us of any areas of concern or offer any suggestions to improve the UK DonorLink register service, or if you wish to commend it, then please contact the Project Manager by post, e-mail or telephone:

UK DonorLink,
31 Moor Road,
Headingley,
Leeds,
LS6 4BG.
Tel: 0113 278 3217
or e-mail: info@ukdonorlink.org.uk

Terms Used

People born as a result of the use of donated sperm, eggs or embryos are referred to in this leaflet as donor-conceived adults.

People who donated sperm, eggs or embryos are referred to as donors.

Data Protection Act Statement

All information retained by UK DonorLink is for the sole purpose of linking donor-conceived adults, donors and genetically related half or full siblings. Any information, personal records or DNA results will not be used for any other purpose. The UK DonorLink register is a secure database and meets with the guidelines set out under the Data Protection Act 1998.



This leaflet can be made available in other formats: large print, audio, Braille and other languages. Please ask for further information.

UK DonorLink

UK Voluntary Information Exchange and Contact Register Following Donor Conception Pre-1991



UK DonorLink, 31 Moor Road, Headingley, Leeds, LS6 4BG

The UK DonorLink project is established and managed by After Adoption Yorkshire.

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