

# ***UK DonorLink***

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



*Annual Report 2008/09*

## 1. Introduction

1.1 UK DonorLink (UKDL) is a pilot contact Register set up to enable people conceived through donated sperm, and/or eggs, their donors and half-siblings to exchange information and, where desired, to contact each other. The Register is available throughout the UK and is specifically intended for anyone over the age of 18 who donated or was conceived prior to the enactment of the Human Fertilisation and Embryology Act in August 1991.

1.2 The initiative is funded by the Department of Health and was launched in London on 21<sup>st</sup> April 2004 by the then Public Health Minister, Melanie Johnson.

1.3 UKDL is managed by After Adoption Yorkshire (AAY). AAY is a regional, independent charity specialising in adoption which provides a full after adoption support service throughout the Yorkshire and Humberside region. AAY also has staff with experience and knowledge of donor conception issues.

1.4 As well as advising on the progress of the project, this Annual Report, covering the fifth full year of operation since the Register's launch, will continue to help in the review of the development of the Register. Further annual reports will be submitted throughout the life of the project.

## 2. Financial Situation

2.1 The Register has been funded through annual grants since 2003. Details of these have been reported in subsequent annual reports.

2.2 Funding of £85,000 was awarded for the year 2008/09 and the budget was brought in on target in the financial year end 31<sup>st</sup> March 2009.

## 3. Staffing

3.1 Project management is provided by the Chief Executive of After Adoption Yorkshire (4 hours per week). The project manager provides direct management and supervision to the project co-ordinator; holds full managerial responsibility for the project and is accountable to the AAY Board of Trustees. The current post holder, Lyndsey Marshall, has been in this role since the inception of the project but has tendered her resignation with effect from the end of July 2009.

3.2 In addition to the project manager, the Register is staffed by 30 hours per week of project co-ordinator time. During the year 2008/09, the post was occupied by Chrissie Gunter (22½ hours) from September 2008, together with Chris Tidy (7½ hours) from April 2009. The post holder's duties include:

- dealing with all initial enquiries
- undertaking direct work with individuals through the registration process and beyond
- liaising with sessional staff - both to arrange for them to see individuals and to offer professional consultation
- consulting with the lab that provides the DNA testing
- liaising with the Department of Health, the HFEA, other interested bodies and the general public
- advertising and promotion of the project
- Work is also extensive in relation to interest from the media.

3.3 The project is supported by a 21 hour per week administrative support post. The current post holder is Sue Clark who joined the project in October 2008.

3.4 The project co-ordinator post is supported by a national network of 12 sessional workers who have all been recruited by person specification and job description. Two days of training were provided prior to the launch of the Register and one day during each subsequent year of operation. Sessional staff duties include:

- seeing individuals if requested for counselling about the implications of registration and/or information exchange and contact following matching
- witnessing DNA sample taking
- offering information, support and advice.

3.5 Specialist IT time is bought in to maintain and develop the Register. Simpleplanet Solutions supports the work of UKDL in relation to the website whilst Grant McGregor Ltd offers technical support. Promotion and marketing of the project are undertaken primarily by project staff although some specialist input was purchased this year.

## **4. Advisory Group**

4.1 The Advisory Group was established at the beginning of the project, under the Chair, Marilyn Crawshaw from the University of York, who is also a Trustee of AAY and acts as Link Trustee to the AAY Board of Trustees. Marilyn has long practice and academic experience and interest in fertility and donor conception issues and has written and contributed to papers on the subject.

4.2 The Group's role is advisory only; it does not carry managerial or other accountability for the work of the project. Terms and conditions in relation to the role of the Advisory Group and the After Adoption Yorkshire Board of Trustees were agreed from the outset and were reviewed during 2008/09 with the assistance of both Advisory Group and Registrants Panel members.

4.3 The primary function of the Advisory Group is to engage in the discussion of issues and ideas raised by the project team; to contribute ideas for consideration and to be used for consultation on a range of issues. Members can be approached by the project staff outside of formal meetings. In addition, the Advisory Group Chair offers regular consultation time to project staff about the project (usually at least monthly).

4.4 Following discussion about the composition of the Advisory Group, it now comprises the Chair and three donor conceived adults, three donors and a parent of a donor conceived person, together with Jennie Hunt, a long-standing professional working in the infertility counselling field and who chaired the working group 'Opening the Record'. There is also provision for the Trustees to appoint additional members as appropriate, including a place specifically for an individual with relevant academic expertise.

4.5. Given the sensitivity of the subject and the high media attention, those personally affected by donation may opt for their identity not to be made public. The members for the year in question decided against taking up this option. Representatives of the Department of Health and HFEA are invited to attend but are not members of the Group, similarly the project team members.

## **5. Registrants Panel**

5.1 A Registrants Panel, which was established in 2007 to reflect the increased interest among registrants of being involved actively in the running and development of the service, meets twice yearly.

5.2 The Registrants Panel comprises donor conceived adults and donors and membership is open to all registrants. Since its inception, it has been chaired by Marilyn Crawshaw and is also attended by members of the project staff. It is anticipated that this will change, with registrants themselves taking over the full running of the Panel with input from the adviser and staff on request.

5.3 Meetings are held currently on the same day as the Advisory Group, thus enabling all to meet together over a shared lunch. This has worked

well.

## 6. Equipment and IT

6.1 There has been no capital expenditure this year.

6.2 The IT company, Simpleplanet Solutions, continues to develop and maintain the website, which is used for information, press releases and news, ensuring that it is as current and informative as possible. The facility to register on-line has continued to be the preferred registration route with more than 90% of registrants joining the Register in this way.

6.3 Due to the nature, content and wording used of necessity on the project, UKDL continues to receive many spam e-mails. Work is in hand to try and block such e-mails more effectively whilst allowing genuine e-mails from registrants and others interested in the website to be delivered.

## 7. DNA Testing

7.1 The current contract continues with the LGC Laboratory.

7.2 The fee levied by the lab for analysis of the DNA test is £75.00 + VAT although this is waived for biological parents. Any registrants in financial hardship can also have their fee waived or reduced.

7.3 Although Y chromosome testing for male registrants has been offered since 2008 in conjunction with the standard DNA test at an additional cost of £76.60 + VAT, this has had a very low take up. This test is particularly helpful in establishing paternal types that are passed on in the male line.

7.4 LGC continue to run the computerised database of all registrants' DNA that replaced their manual system in 2007.

7.5 As we have reported previously, DNA 'matching' of a donor to a donor conceived person is the most straightforward form whereas donor conceived half-sibling to half-sibling 'matching' is extremely complex. Both are considerably enhanced where the DNA of the biological parent is also available. Any additional information made available by registrants is used alongside the technical DNA analysis to aid the interpretation of the results.

7.6 UKDL works with the lab staff to try and ensure that decisions about whether there is a 'match' are as fully informed as possible and that re-

results are provided in lay language. This is not easy as there can never be full certainty. Hence a written disclaimer is provided when results are shared as well as verbal explanations to this effect. UKDL is acutely aware of the potential risk to the wellbeing of registrants being given results that suggest a high probability of a match only to be followed by findings in later matching runs that reduce the probability. As we have said in previous reports, this remains, in our view, one of the most challenging aspects of the service.

## **8. Advertising Publicity and Media Work**

8.1 During the year UKDL has been involved in the following media and publicity work and has:

- Run banner adverts on the 'Friends Reunited/Genes Reunited' website in December 2008
- Commissioned a local advertising agency to design new advertisements specifically aimed at donors which featured in The Times and Daily Telegraph newspapers in March 2009
- Featured in the Guardian newspaper and Cosmopolitan magazine articles about donor conception
- Liaised with producers/researchers of BBC programmes which have featured our Registrants i.e. Saturday Live Radio 4 and "Who's my half brother, who's my half sister" also on Radio 4
- Advertised in The Big Issue and a West Yorkshire health magazine
- Regularly liaised with the media to help them understand the role of UKDL and to promote debate about donor conception and taken advice from our advertising agency on how to promote UKDL to potential Registrants.
- Extended our media register of registrants who are willing to give identifying or non identifying information/interviews to the press

8.2 UKDL continues to receive many press enquiries and enquiries for TV and radio researchers - often in response to current media interest in donation. Whilst UKDL always responds to media requests, this can take up a disproportionate amount of time when compared with the publicity received.

## **9. Links with the Human Fertilisation and Embryology Authority (HFEA)**

9.1 Links between the HFEA and UKDL have continued, albeit not at a frequency that UKDL would prefer. As referred to earlier, representatives of the HFEA attend the UKDL Advisory Group (although are not members) and members of the staff together, occasionally, with the Ad-

viser, have met with HFEA Senior Managers. In June 2009 Professor Lisa Jardine, Chair of the HFEA, and Alan Doran, Acting Chief Executive, visited the UKDL offices.

9.2 UKDL also maintains periodic links with those HFEA staff who deal with enquiries of the HFEA Register as enquirers to each service sometimes require re-directing to the other.

9.3 In October 2008, Marilyn Crawshaw was invited to present a paper on the work of UKDL to the HFEA Annual Conference and in December 2008, Marilyn Crawshaw, Chrissie Gunter and Chris Tidy gave a lunch-time seminar to all HFEA staff.

9.4 UKDL has continued to argue for the need for 'searching' and intermediary services to be provided to those making enquiries of the HFEA Register - i.e. going beyond making the 'offer' of counselling that is a statutory requirement - but has to date been unsuccessful in this. The HFEA is proposing only to provide information about counselling services but not to provide any services beyond the provision of the information requested.

## **10. Referrals and registrations**

10.1 We have continued to find that there are large variations in the speed at which people complete the registration process. The majority of people use the on-line system. Some complete the paperwork and the DNA test quickly and with minimum input from UKDL staff; some opt to see one of the UKDL staff for help with the process (including witnessing the DNA test) and/or to talk through the implications, sometimes over several months; some stop and start the process several times; some have suspended the process and are yet to resume.

10.2 At the end of the reporting year, i.e. 30<sup>th</sup> June 2009, there were approximately 230 people registered or considering registering with ages ranging from 18 to 74.

10.3 Out of the 230 people registered or in the process of considering registering, there were 143 people who were fully registered with UKDL, 87 who were in the process of registering. 155 of those registered or in the process were Donor Conceived Adults and 73 were Donors. 44 Birth Mothers had contributed their DNA as had 2 genetically related siblings. To date the vast majority of Donors are Sperm Donors with only 1 Egg Donor registered with UKDL. One person registered was conceived from Egg Donation. Currently, UKDL do not have any persons registered who

were born as the result of Embryo Donation. Egg/Embryo donation only became more established towards the latter end of the period covered by UKDL.

10.4 'Matches': During this fifth year, there have been further 'matches' between half siblings. This brings the total of 'matches' since the launch of the Register between half siblings to nineteen. To date there have been no donor to donor conceived adult links.

10.5 As well as offering information and support during the registration process, registrants are also offered ongoing contact or renewed contact at any stage that they wish. Additionally, up to 3 sessions with one of the regional sessional support staff are available for support or counselling free of charge. When information is provided to indicate that there is a high probability of a genetic match, support is again offered.

10.6 It is our experience that almost all registrants undertake a DNA test. Of the small number who decide against, all have said that they might consider doing so in the future.

10.7 The ratio of males to female donor conceived adults at the end of the fifth year of operation remains as previously noted - i.e. approximately 30% male and 70% female. No obvious reason for this has emerged though research among adult adopted people who 'search' has also found a higher proportion of females.

10.8 Approximately 8% (a slight decline) of donor conceived adults live overseas though it is not clear if those who do so have moved as adults intending to live abroad permanently or emigrated with their parents as children. The majority of those living abroad are in the USA, Canada, Australia and New Zealand.

## 11. Service Support

11.1 In addition to direct service contact, the UKDL staff team is involved in a significant level of e-mail, telephone and written contact with possible and actual registrants. The website continues to be the most favoured route through which registrants and potential registrants make their first contact with the service.

11.2 UKDL received several enquiries from parents of children conceived post 1991 during the year. They were given information in relation to the HFEA and support groups such as DC Network. UKDL also continues to receive calls from mothers of donor conceived adults who are considering telling their children of their origins. UKDL offers advice and sup-

port to parents in this situation and suggestions of reading materials to help with this.

11.3 The Register strives to provide a comprehensive service to all enquirers and registrants. This includes advice, support and guidance from initial enquiry through the registration process and, when requested, assistance and support with undertaking and witnessing the completion of the DNA sample. Support is also available following registration, including at matching and/or information exchange.

11.4 Whilst the majority of registrants decline the offer of 'counselling', many take up the offer of advice and support, particularly through the completion of the DNA test. All registrants are offered a personal discussion when they register about issues relevant to them or about the operation of the Register.

## 12. Legal and Policy Issues

12.1 There have been important legislative developments this year, notably the passage through Parliament of the Human Fertilisation and Embryology Act 2008.

12.2 UKDL used the opportunity to lobby on a number of areas of concern to registrants and staff. These included: (i) the need for pre-1991 records of donor conceptions to be secured; (ii) the need for pre-1991 donors to be afforded the same legal protection as that for those who donated after the enactment of the Human Fertilisation and Embryology Act 1990 in August 1991 and (iii) the need for intermediary services to be available free of charge to people seeking those with whom they are genetically related through donor conception. Sadly, our lobbying proved unsuccessful although we were made a grant of £10,000 from the Department of Health to secure QC's advice about inheritance liabilities (this is ongoing).

12.3 The new Act includes provision for the HFEA to be granted the statutory power to run, or commission the running of, a Voluntary register for those affected prior to August 1991 (currently the service provided by UKDL). UKDL has been pressing for an assurance from the HFEA that they will not levy charges on those using the Register when they take over this function and to date we have not secured that assurance. We have also argued that the Register should continue to be open to those currently eligible and that it should continue to be allowed to develop as responsively to users' needs as possible.

## 13. Future Developments

As well as an ongoing review of all aspects of the Register service there are a number of specific areas of development planned for 2009/10 namely:

- Move the running of the Registrants Panel more fully to registrants themselves
- Review the registration process
- Overhaul the Register database to make it more fully responsive to service needs
- Review the website and enhance its use
- Review the contractual arrangements for the DNA service
- Maximise publicity opportunities to increase public awareness of UKDL



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Pre-1991

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