UK DonorLink

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

Annual Report 2009/10

It is with great sadness that we start this Report with the announcement of the untimely death of Judith Calvert in November 2010. Judith was one of the founding staff team in the early days of UK DonorLink and her warmth, compassion, wisdom and commitment were second to none. Although she ceased her work for UKDL some time ago, she retained a keen interest in its development.

UK DonorLink Annual Report
1st July 2009 to 30th June 2010

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 21st 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 sixth 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 2009/10 and the budget was brought in on target in the financial year end 31st March 2010.

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(s); holds full managerial responsibility for the project and is accountable to the AAY Board of Trustees. The current post holder, Freda Atherton, has been in this role since the end of March 2010 and ended a period of time in which the service, along with the rest of AAY, was managing with substantially reduced senior management input while a replacement for the previous post holder, Lyndsey Marshall, was found.

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 2009/10, the post was occupied by Chrissie Gunter (22½ hours) who joined the project in 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 Laboratory 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
- dealing with media and any other enquiries

3.3 The project is supported by a 21 hours 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.

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 The Advisory Group comprises the Chair, three donor conceived adults, three donors, 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 HFEA 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. Membership is open to all Registrants. At its inception it was chaired by Marilyn Crawshaw (adviser) and attended by members of the project staff. However, during this year, Registrants themselves took over its running with input on request from the adviser and staff.

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

5.4 The Registrants Panel hosted its first 'open event' in London in April 2010. Donor conceived adults and donors were invited, providing the opportunity for some to meet others directly affected by donor conception for the first time. The project co-ordinators and adviser were also invited. It is hoped that this will become an annual event.

6. Equipment and IT

6.1 There has been no capital expenditure this year.

6.2 The IT company, Simpleplanet Solutions, continues to maintain the website, which is used for information, press releases and news.

6.3 UKDL staff would like to have developed the website further this year but pressure of work has prevented this.

7. DNA Testing

7.1 LGC Laboratory continues to provide the DNA service, including maintenance of the computerised database. A new service level agreement with them was agreed in June 2010.

7.2 The fee levied by the lab for analysis of the DNA test for this reporting period is £75.00 + VAT although this is waived for biological parents. Any Registrants in financial hardship may 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 (for this reporting period), this continues to have a very low take up. This test is particularly helpful in establishing paternal types that are passed on in the male line.

7.4 As we have reported previously, establishing a 'link' through DNA between a donor and a donor conceived person is the most straightforward form whereas donor conceived half-sibling to half-sibling 'linking' is extremely complex. Both are considerably enhanced where the DNA of the biological parent is also available. Any additional information made available by Registrants, such as where they were conceived, is used alongside the technical DNA analysis to aid the interpretation of the results.

7.5 UKDL works with the Lab staff to try and ensure that decisions about whether there is a 'link' are as fully informed as possible and that 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 likelihood of a 'link' only to be followed by findings in later runs that reduce the likelihood. As in previous reports, we repeat our view that this remains one of the most challenging aspects of the service.

8. Referrals and Registrations

8.1 We continue to find large variations in the speed at which people complete the registration process. Registration on-line has continued to be the preferred registration route (90%). For some, the paperwork and DNA test is completed speedily and with minimum support from UKDL staff; many take up the offer of seeing one of the UKDL staff for witnessing their DNA test and/or to talk through the implications; some take several months to complete the process, going at a pace that seems right for them; some have suspended the process and are yet to resume.

8.2 At the end of the reporting year, i.e. 30th June 2010, there were approximately 317 people registered or considering registering with ages ranging from 18 to 75.

8.3 Out of the 317 people registered or in the process of considering registering, there were 191 people who were fully registered with UKDL, 126 who were in the process of registering. 208 of those registered or in the process were Donor Conceived Adults and 95 were Donors. 63 Birth Mothers had contributed their DNA as had 3 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.

8.4 'Links': During this sixth year, there have been further 'links' between half siblings. This brings the total of 'links' since the launch of the Register between half siblings to twenty-six and two donors, now deceased, have also been identified. To date there have been no donor to donor conceived adult links[1].

8.5 As well as contact during registration, 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 free of charge. When information is provided to indicate that there is a high likelihood of a genetic match, support is again offered.

8.6 It is our experience that almost all Registrants undertake a DNA test, with a small number deciding against but being willing to consider doing so in the future.

8.7 Finally, we can report that, on the advice of the Registrants Panel, we reviewed our registration process and were able to streamline some aspects of it by lowering the requirements for supplying original documents for identification as the project will now accept photocopies.

9. A Pilot Study using lower thresholds for sharing results

9.1 Members of the Registrants Panel (RP) asked during the course of the reporting year that they be given their 'results' at a lower level than that currently being used. After some discussion, it was agreed to run a pilot with all 12 RP donor conceived members to see how such a development would work in practice. UKDL staff had concerns about (i) the resource implications (and hence the impact on processing new registrations and so on) and (ii) the impact on Registrants of being provided with results that might throw up more false positives.

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[1] Please note that by the time of writing this report (January 2011) there have been two 'donor to donor-conceived adult' links made.

9.2 The views of RP members were sought on several different options for a pilot and that survey was completed in April 2010. Results were discussed at both the RP and Advisory Group meetings in May 2010.

9.3 It was agreed by the Manager that the pilot would start immediately that the outstanding DNA results were available from the Lab. The threshold for the pilot was agreed to be set at 1 and above. It was agreed that RP members would be contacted by phone or letter to invite them to make contact with UKDL staff to receive and discuss their results and that Registrants not on the RP who were potentially linked to RP members would be contacted in the same way. RP members were asked to note that the likely involvement of non-RP Registrants would be likely to take up additional time as they would be coming to the pilot completely afresh.

9.4 UKDL staff will be monitoring the impact of the pilot on their workload and will be keen to receive feedback from Registrants on its impact on them.

10. Service Support

10.1 UKDL staff are involved in e-mail, telephone and written contact with possible and actual Registrants as well as face-to-face. Most initial contacts are through the website.

10.2 UKDL continues to receive enquiries from parents of children conceived post 1991 from time to time. They are 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 support to parents in this situation and suggestions of reading materials to help with this.

10.3 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 ‘linking’ and/or information exchange.

10.4 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.

11. Advertising Publicity and Media Work

11.1 During the year UKDL has been involved in the following media and publicity work including two of our Registrants appearing live on the *Victoria Derbyshire Show* on BBC Radio 5 in Oct 2009 and an interview on Real Radio Wales in Feb 2010. Another Registrant appeared on TV on BBC 1 *The Big Questions* programme.

A leading Polish newspaper sent one of their journalists over to the UK to research an article on donor conception. This featured a number of our Registrants and information from UKDL and was published in Jan 2010.

In March 2010 we again ran the advertisements aimed at donors that we had previously run in March 2009 in The Times and Daily Telegraph although the results were not as good as the previous year.

11.2 UKDL continues to receive regular TV, radio, newspaper and magazine enquiries and enquiries. Media interest in donation continues to remain high and can provide the opportunity to raise the profile of the UKDL Register. However, it is also time consuming and, on occasion, articles fail to appear or fail to accurately portray our work.

12. Links with the Human Fertilisation and Embryology Authority (HFEA)

12.1 Links between the HFEA and UKDL were continuing for the major part of the reporting year along similar lines to those previously reported, albeit still at a lower frequency than UKDL would have preferred. A member of the HFEA staff continued to attend the Advisory Group as an observer.

12.2 UKDL staff have maintained awareness of the changes resulting from the implementation of the Human Fertilisation and Embryology Act 2008 in order to keep abreast of developments in the wider world of donor assisted conception services, for example the launch of Donor Sibling Link register for adults conceived after August 1991.

12.3 UKDL has continued to argue for the need for 'searching' and intermediary services to be provided to those making enquiries of both the HFEA Register and Donor Sibling Link – i.e. going beyond making the 'offer' of counselling that is a statutory requirement. For both HFEA Registers, the HFEA only provides information about counselling services (which can then be contracted privately by individuals) but does not provide professional support beyond the provision of the written information requested.

12.4 Shortly before the end of the financial year in March 2010, UKDL was informed by the Department of Health that their application for a three year grant had (unexpectedly) been unsuccessful due to changes in the eligibility criteria for such grants. In April, the then Public Health Minister wrote to the HFEA to invite them to take on the Voluntary Register as allowed for in the new Human Fertilisation and Embryology Act 2008. In that letter, she made clear her view that the piloting of the Voluntary Register had been sufficiently successful to warrant it being put onto a firmer financial footing and the transfer to the HFEA was intended to effect that. A grant for one year only was awarded to cover the transition by April 2011.

12.5 At the end of the reporting period of this Report, a preliminary meeting had taken place between UKDL, Dept of Health and HFEA staff to explore the issues arising from this request and to develop transition plans.

12.6 At the time of **producing** this report (January 2011), there have been significant developments in this matter. UKDL staff and others invested considerable amounts of time from March to December 2010 in producing information for the HFEA to assist them in their task of looking at the different options for running the Register. Many Registrants and others produced testimonials and other evidence as to the importance of the UKDL service.

At the HFEA meeting on 8th December 2010, the HFEA declined the Minister's invitation to take on the Voluntary Register, primarily on the grounds that the Government was not allocating any funds to the HFEA to take on this work; their own existing budget is being reduced; and their own future is uncertain as it has been proposed that they will be abolished during the lifetime of the present Parliament. HFEA members were, however, very supportive of the existence of the Register and the work of UKDL staff. This is a constantly changing situation, leaving some uncertainties around the future of the voluntary register. We are in regular contact with the Department of Health about this.

13. Legal and Policy Issues

13.1 As noted above, the recently enacted Human Fertilisation and Embryology Act 2008 was implemented in parts during 2009-2010, though none of direct relevance to UKDL (though see also 12.6 above).

13.2 The HFEA have decided to conduct a Donation Review Public Consultation from January to April 2011, asking for views about various aspects of current donor conception services. UKDL have pointed to the importance of the inclusion of donor conceived adults and past donors in the consultation.
Anyone with an interest can register to receive up-to-date information by going to www.hfea.gov.uk/donationreview. The consultation will be on-line only, reflecting the current financial constraints.

14. Future Developments

Last year, we reported that we intended to work on several aspects of our service and report progress as follows:

- Move the running of the Registrants Panel more fully to Registrants themselves – DONE
- Review the registration process – DONE
- Overhaul the Register database to make it more fully responsive to service needs – ONGOING
- Review the website and enhance its use – NOT DONE due to workload pressures
- Review the contractual arrangements for the DNA service – DONE, NEW CONTRACT IN PLACE
- Maximise publicity opportunities to increase public awareness of UKDL – ONGOING

Given the uncertainty surrounding the future of the voluntary register service, our priority for 2010-2011 is to try to secure it and, to that end, this year we are not setting ourselves other targets.