

Cruwys news

The day-to-day activities of the Cruwys/Cruse one-name study with occasional diversions into other topics of interest such as DNA testing and personal genomics

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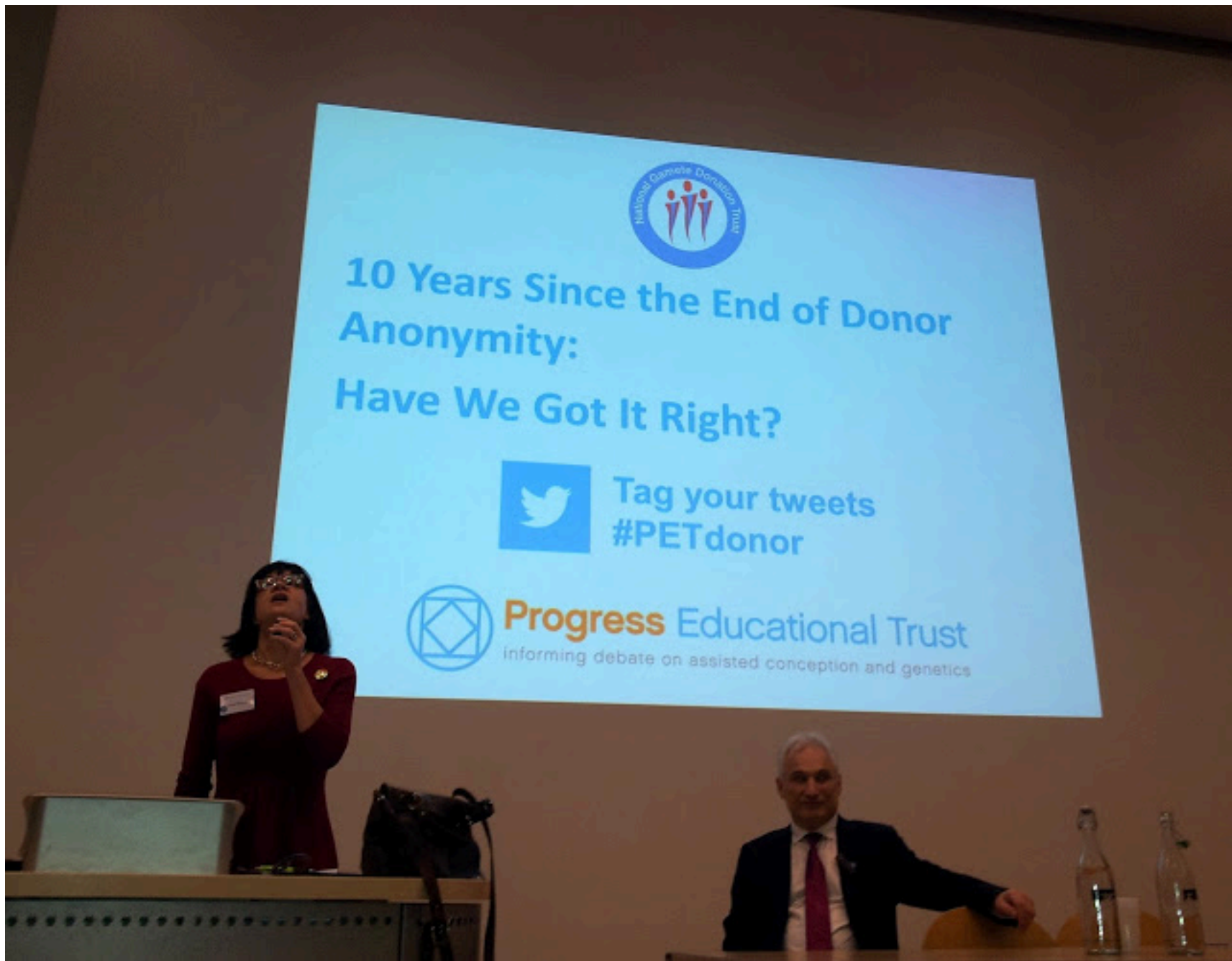
Disclosure

TUESDAY, 10 NOVEMBER 2015

Ten years since the end of donor anonymity: have we got it right?

Last week I attended a public meeting organised by the Progress Educational Trust to mark the 10th anniversary of the change in the law in the UK which gave donor-conceived people the right to access information about their birth once they reach the age of 18. The meeting [10 years since the end of donor anonymity: have we got it right?](#) was held at the Institute of Child Health in London. I've shared below my notes from the meeting and some of my photos. It is a very important subject and these issues should be the subject of a much wider debate.

Sarah Norcross, Director of the Progress Educational Trust, opened the meeting and introduced Charles Lister, the Chairman of the National Gamete Donation Trust, who was chairing the meeting.



Sarah Norcross from the Progress Educational Trust opens the meeting and introduces Charles Lister.

Charles Lister described the evening as an event celebrating ten years since the end of donor anonymity. He shared a moving quote from a 2004 speech by Melanie Johnson, the then Minister of Public Health:

"Clinics decide to provide treatment using donors; patients make a decision to receive treatment using donors; donors decide to donate. Donor-conceived children, however, do not decide to be born – is it therefore right that access to information about the donation that led to their birth should be denied to them?"

The new law ending the right to donor anonymity in the UK came into effect on 1st April 2005. Prior to the change it was predicted that there would be a drop in the number of donors coming forward, but that hasn't come to pass though there are still not enough donors. Children conceived before that date can access their data if the donor makes the information available. Lister emphasised that the rights of the children should be the prime consideration.

Five panellists were given the opportunity to make a seven-minute presentation and this was followed by an extended session in which members of the audience were invited to comment and ask questions of the panellists.

Juliet Tizzard, Director of Strategy at the Human Fertilisation and Embryology Authority (HFEA)



The Church of the Holy Cross at Cruwys Morchard, Devon

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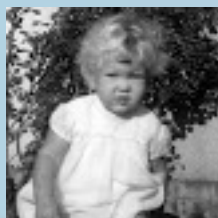
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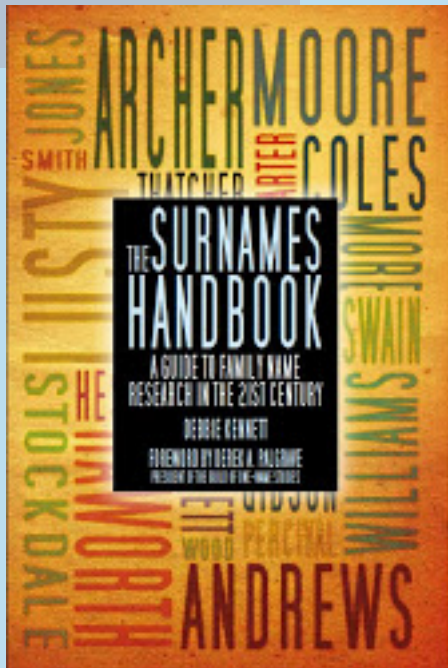
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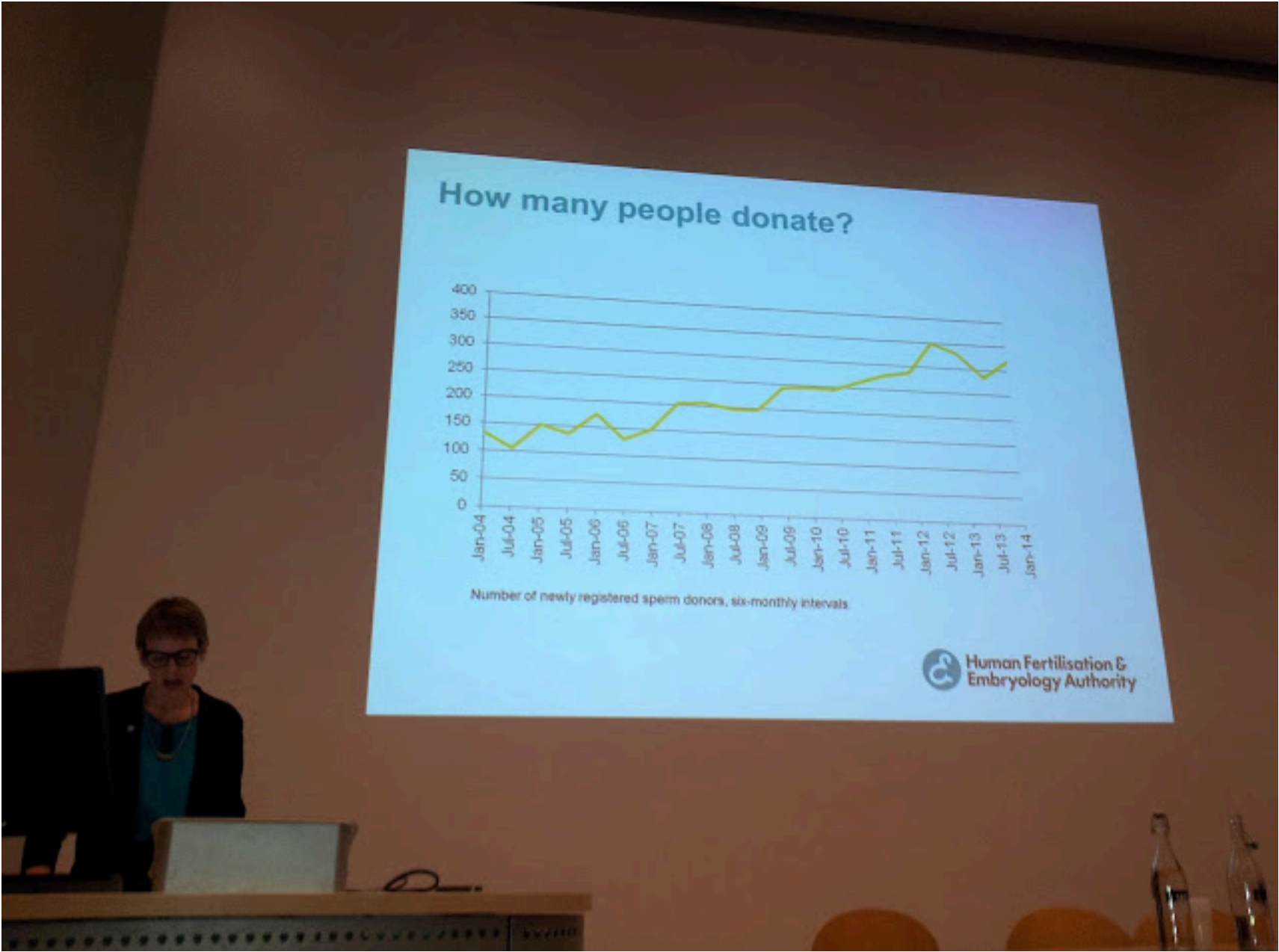
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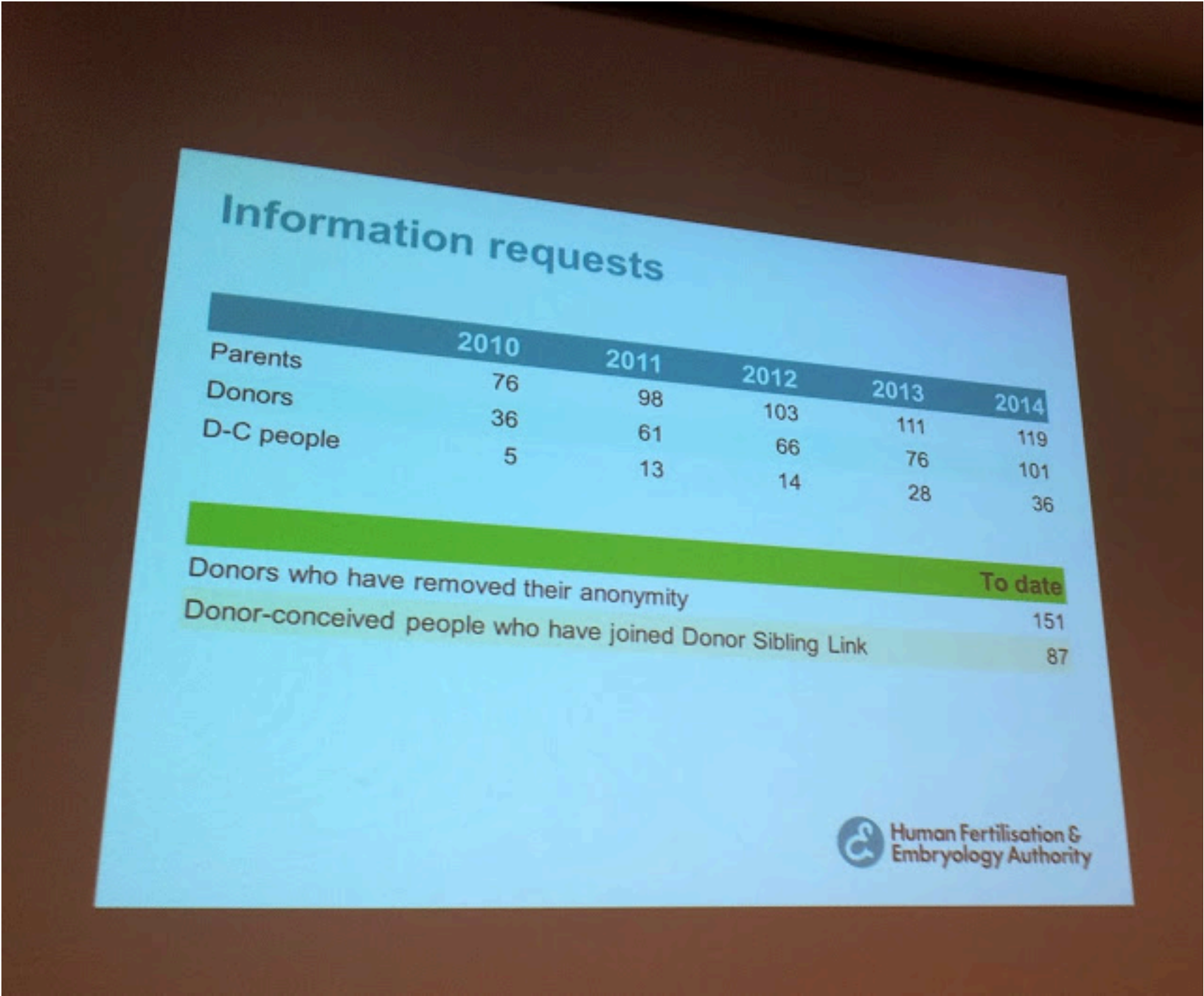


Juliet Tizzard presented data showing that the number of newly registered sperm donors has increased between 2004 and 2014.



Jo Tizzard: How many people donate?

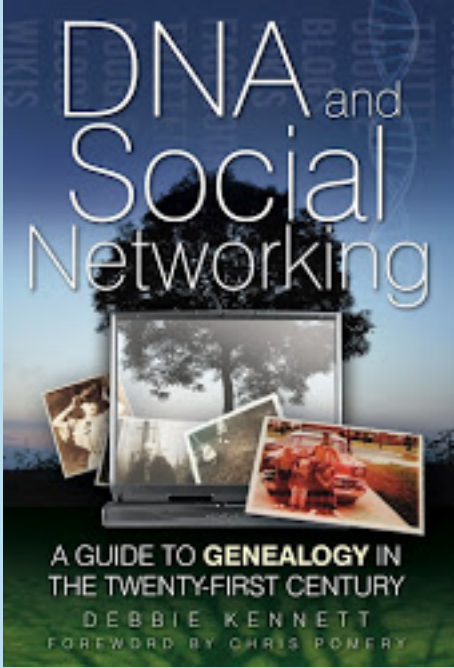
She told us that donors can retrospectively remove their anonymity. One third of the sperm used in the UK is imported from overseas, primarily from the US. Denmark is the next biggest contributor. There were 2050 babies born in the last year as a result of sperm and egg donation. HFEA have services available to talk to people about what they might expect from the treatment. She also presented figures showing the number of information requests over the last four years. To date 151 donors have removed their anonymity. Eighty-seven donor-conceived people have joined [Donor Sibling Link](#).



Juliet Tizzard: Information requests.

Joanna Rose, donor-conceived person

Joanna Rose was conceived from an anonymous donor conception in the 1970s. It was largely thanks to a legal challenge she brought in 2002 regarding the disconnection between the identity and the genetic kin of donor offspring that the law on donor anonymity was changed. Joanna has completed her PhD *A Critical Analysis of Sperm Donation Practices*. A copy of the thesis can be downloaded from the [Confessions of a Cryokid blog](#). Joanna began by citing the words of a song written by Kevin Staudt on his experience of growing up as a donor-conceived child and the search for his father.



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Family Tree DNA have just announced at their conference the introduction of a new Y-chromosome DNA test to be known as the Big Y. The new te...

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The news of Prince William's Indian DNA was featured in a number of newspapers around the world on Friday. The Daily Mail reported that "DN...



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I have now taken an autosomal DNA cousin-matching test at all three testing companies – 23andMe, AncestryDNA and Family Tree DNA. With th...



[My updated ethnicity results from AncestryDNA - a British perspective](#)



Jo Rose: The words of Kevin Staudt's song "Novum".

Prior to the event Jo had requested that all attendees watch a recording of Kevin's song. You can listen to the recording on YouTube.



Joanna gave a powerful and heartrending speech about the pain of being a donor-conceived person. She spoke of her friend Narelle Grech who campaigned for fifteen years against donor anonymity in Australia. Narelle was diagnosed with Stage IV stomach cancer, but she was lucky to find her biological father just six weeks before she died.

Joanna told us that she had no support when she brought her court case, and she used up all her inheritance money to bring the action. When she asked about her father she was told that he was an "irrelevant third party". Jo pointed out that donor-conceived children do not have any representation on HFEA. Consequently HFEA have no accountability. She claimed that many HFEA members have a conflict of interest because of their work with the infertility industry. Jo concluded by recommending that we should change from adult to child-centric practices. There must be multi-disciplinary protections to counter the conflict of interests from the infertility industry and its users. Services need to be provided to help address the problems of donor offspring.

AncestryDNA announced last week that they were starting to roll out a free update to their ethnicity results. I noticed today that my upda...

A confusion of SNPs

This article is for experienced genetic genealogists and requires a reasonable understanding of SNPs and haplogroups. The launch of the ...



The BIG Y roll out – the SNP tsunami is on its way!

The genetic genealogy

community has been eagerly anticipating the arrival of the so-called SNP tsunami for several months and it now see...



The new Family Finder test from FTDNA

In February this year Family Tree DNA

announced the introduction of an exciting new DNA test called the Family Finder. The test is being rol...



Richard III - a king is found

I have been fascinated by the story of Richard III

ever since reading the intriguing historical detective story The Daughter of Time by Jo...

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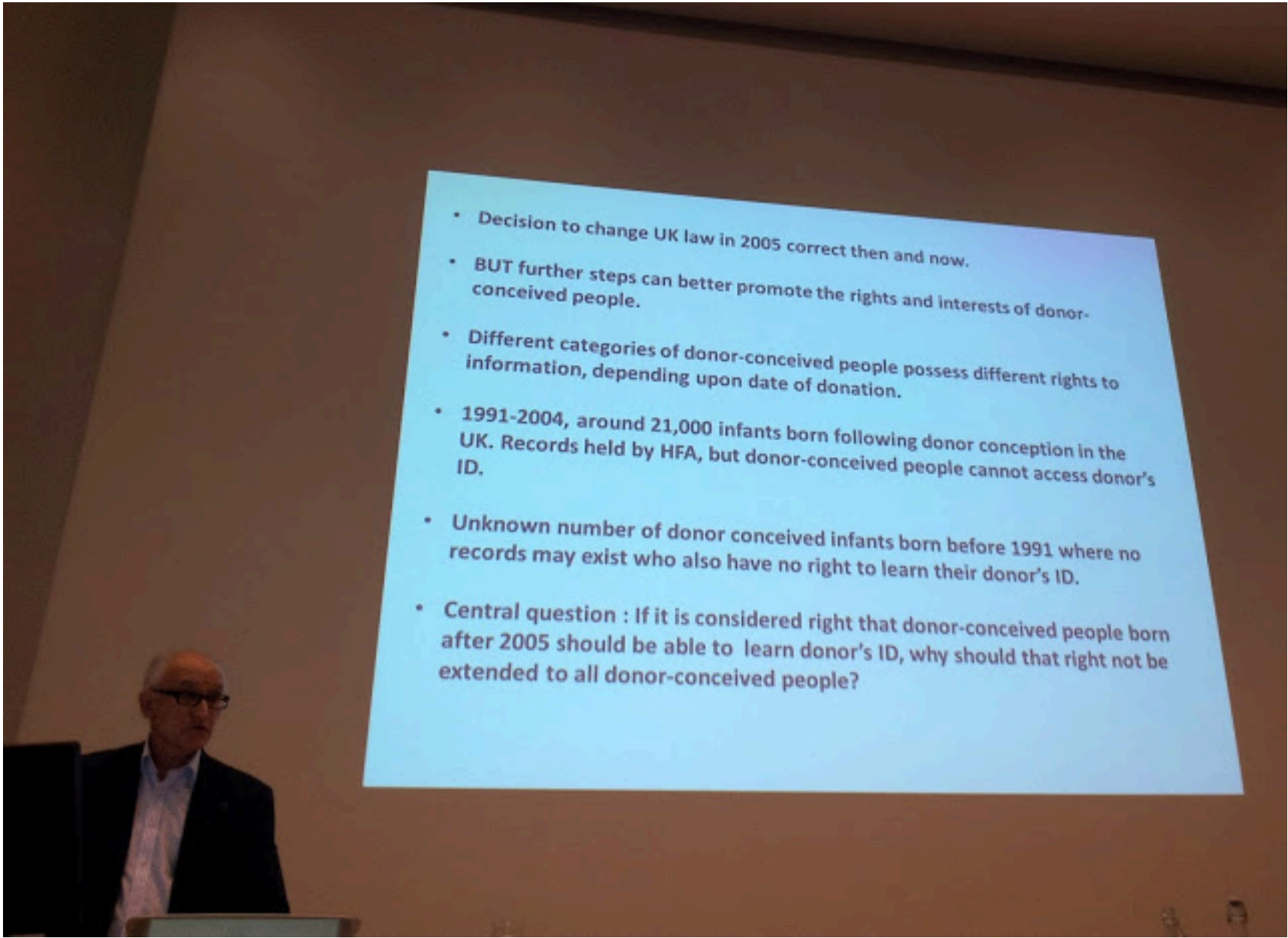
Chris Tyler-Smith (1)



Jo Rose: Conclusions and recommendations.

Eric Blythe, Emeritus Professor of Social Work, the University of Huddersfield

Eric Blythe commented that the change in the law is only the first step. We now have a situation where different categories of donor-conceived people have different rights depending on the date of donation. There were 21,000 infants born between 1991 and 2004 before the law was changed. HFEA hold the records but donor-conceived people can't access the donor's ID. There are an unknown number of donor-conceived children born before 1991 where no records may exist. If it is considered right that donor-conceived people born after 2005 should be able to learn their donor's ID, should this right not be extended to all donor-conceived people?



Eric Blythe: Moving forwards

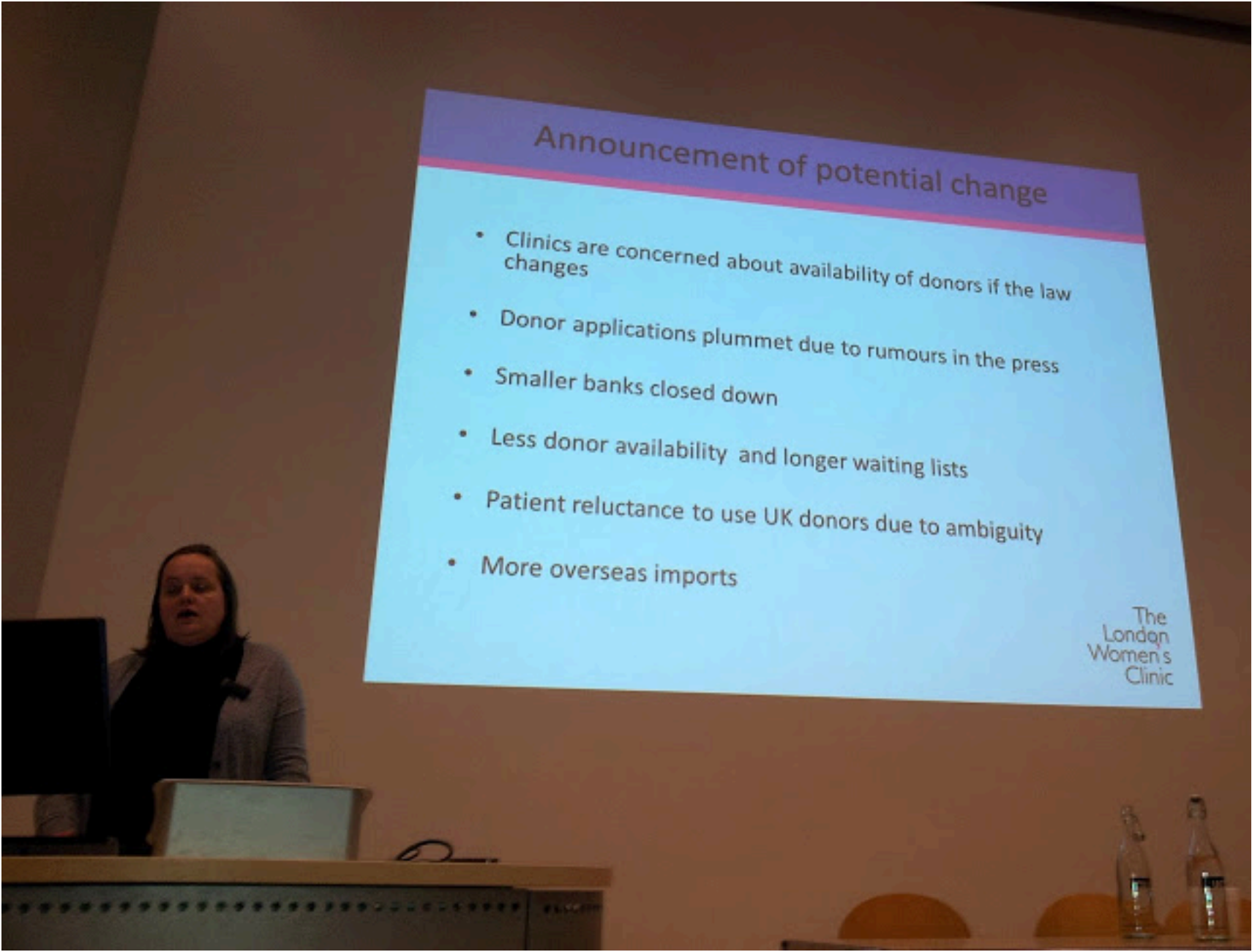
The traditional response has always been that donors who donated prior to 2005 consented on the basis of anonymity. Retrospective disclosure without their consent would be an unreasonable breach of their privacy. However, this means that the donors' rights trump the rights of the donor-conceived person. There is no reason why these potentially conflicting rights should be prioritised in this way and why all donor-conceived people should not be treated equally as far as is humanly possible. In Victoria, Australia, the [right to donor anonymity was rescinded retrospectively](#). (We were later told that this law is known as [Narelle's Law](#) in memory of Joanna Rose's donor-conceived friend Narelle Grech.) There is no reason why other jurisdictions should not follow the lead of Victoria.

Venessa Smith, London Women's Clinic and London Sperm Bank

Venessa stood in at the last minute for the advertised speaker Jo Adams who was unable to attend because of a family crisis. Venessa spoke about how the change in the law had affected fertility clinics.

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- [Hampshire](#) (1)

Donor applications plummeted due to rumours in the press and some of the smaller banks closed down. There is less donor availability and longer waiting lists. Patients are reluctant to use UK donors due to the ambiguity and consequently there are more overseas imports.



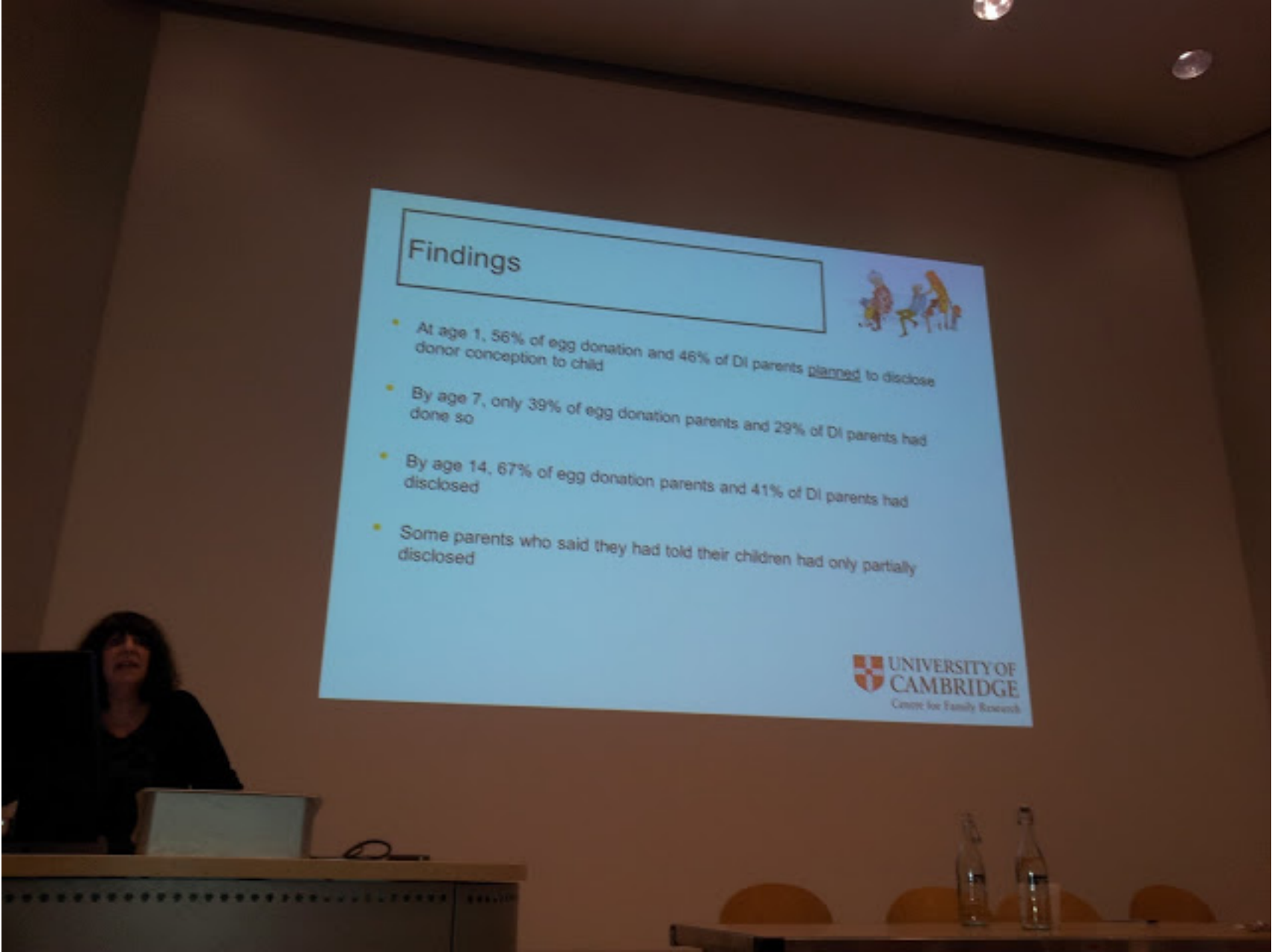
The people coming forward to be sperm donors are different today. The focus is much more on the donor experience. In the past men used to donate for "beer money". Now young professionals with families are donating altruistically. Pre-2005 the focus was on a successful outcome. Now the focus is on the welfare of the child.

Susan Golombok, Professor of Family Research and Director of the Centre for Family Research, the University of Cambridge

Susan Golombok reviewed the last 30 years of research on donor conception. The [European Study of Assisted Reproduction Families](#) was the first longitudinal study of donor insemination (DI) families. There were 111 DI families included in the study from the UK, Spain, Italy and the Netherlands. The children were all born in the 1980s. The families were assessed when the children were aged six, twelve and eighteen. At the age of six not one of the families had disclosed the donor conception to the child. At age twelve fewer than 10% of the parents had disclosed the information. At eighteen no further parents had disclosed.

The UK Longitudinal Study of Assisted Reproduction Families was conducted 15 years after the first study. The researchers looked at 50 DI families and 51 egg donation families. The parents were interviewed when the children were one, two, three, seven, ten and fourteen. The children who were aware of their donor conception were interviewed at seven, ten and fourteen years. At age one 56% of egg donation parents and 46% of DI parents planned to disclose donor conception to the child. By age seven only 39% of egg donation parents and 29% of DI parents had done so. Seven is the key age when most adopted children become aware of their adoption. By age fourteen 67% of egg donation parents and 41% of DI parents had disclosed. However, some parents who said they had told their children had only partially disclosed.

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Susan Golombok: Donor conception research findings.

The children's reaction to disclosure varied from lack of interest to curiosity but no child responded in a negative way. No parents regretted disclosure. However, just because the parents say they have disclosed it doesn't mean that the child understands the implications. Also, although parents generally tell their children that they were conceived by in vitro fertilisation they often don't reveal that the child was born by egg or sperm donation.

Susan Golombok then shared some slides showing children's understanding of donor conception at age seven and age ten, and how they felt about being donor conceived. Although the children claimed to feel fine, it was notable that many of them had not discussed the issue with their friends. One ten-year-old girl said: "That's the only secret that I haven't told any of my friends because I don't really want anyone to know". At age fourteen their feelings ranged from lack of interest to curiosity about the donor's characteristics. They did not reject their father. The lack of genetic relatedness was insignificant in terms of their feelings for him.

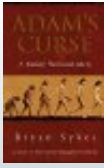
Finally Susan Golombok shared the findings from a study of children born following the removal of donor anonymity. Forty-seven two-parent families and 31 solo-mother families with children aged between four and seven years were included in the study. Sixty-four percent of two-parent families had not disclosed and 45% of solo-mother families had not disclosed. Almost all solo-mother families planned to disclose. Of the two-parent families who had not disclosed around half were uncertain about disclosure or were not planning not to tell.

Audience questions and panel responses


A heated discussion followed the presentations. The first questioner, Elizabeth Howard, a donor-conceived person, raised a number of issues about Susan Golombok's research. The sample sizes were all very small. All her research has been done on children up to the age of 18, and had generally presented a fairly rosy picture of donor conception. However, no research has been done on donor-conceived adults, yet it is adults who are often the most affected by these issues. People only start to wonder about their heritage when they start a family or in later life. A court case has established that some of the research was a breach of human rights and that proper consent had not been obtained from the children. It was also suggested that Golombok's research was biased because some of it is supported by the fertility industry. One study was funded by Stonewall. In contrast, there is no money for supporting donor-conceived adults. Golombok robustly denied that there was a conflict of interest. Whatever the truth of the matter it is clear that there is an urgent need for research to be done on the long-term effects for donor-conceived adults. I suggested that it should be possible to make use of the large 23andMe database which now has records for over one million people. 23andMe would easily be able to identify through questionnaires a large cohort of sperm-conceived adults in their database who would be interested in participating in research. Unfortunately there seems to be a general lack of funding available to support such research.

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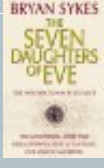
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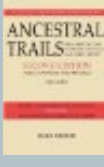
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Privacy



The panel. From left to right: Juliet Tizzard, Susan Golombok, Jo Rose, Venessa Smith and Eric Blythe.

Jo Rose commented that donor conception is human experimentation which has been done without the consent of the child and it is a violation of human rights. Donor-conceived children do not even have the same basic rights as adoptees. In 1975 the law was changed so that adopted children have the right to access their birth information but this privilege was only granted to donor-conceived children in 2005.

Gerard, a donor from New Zealand, has six donor offspring. Anonymity was removed in New Zealand in 1990. He did not think that the law should be changed retrospectively but suggested that there should be a public campaign for donors to come forward. However, with the increasing availability of genetic ancestry testing and the ever-growing genetic genealogy matching databases, donor anonymity can no longer be guaranteed. With a match with a close cousin up to about the third cousin level it is often possible to trace the genealogy forwards to identify a likely candidate for a biological father. As many children were not told they were donor conceived people should also be prepared for family secrets being revealed unexpectedly as a result of a commercial genetic ancestry test. (For an example of one such case see the story of Thomas Lippert, [an artificial insemination nightmare that was revealed by genetic ancestry testing](#). Further coverage of the story [can be found here](#).)

The Children's Act specifies that the rights of the child should always come first. However, despite the change in the law there is no legal requirement for parents to tell their children that they are donor-conceived. There is a divorce in reproductive research between the best interests of the child and the interests of the parents and the fertility clinics. Some clinics actively encourage women to go abroad. The parents don't realise that the laws are different overseas.

Emma Cresswell, a donor-conceived child, made a strong case for the need to reform the birth registration system. She proposed that the information about the biological father and the adoptive should be recorded on the child's birth certificate. The clinics must insist that the parents tell the children. Emma was [the first donor-conceived person in Britain to have her father's name struck off her birth certificate](#). She doesn't know the name of her biological father and the space is now a blank.

Parents of donor-conceived children and those working in infertility research were more cautious about legislative changes. It was suggested that parents should be given encouragement to tell their children before conception. They should talk to the child about their conception as soon as as they are born. Juliet Tizzard suggested that parents should be given the tools to build up their confidence to tell the child.

Conclusions

The subject of donor conception is a highly charged and emotive issue. I find it difficult to remain objective on the subject because I am exposed on an almost daily basis to adoptees and foundlings on genetic genealogy mailing lists and in Facebook groups who have been denied access to their biological heritage and who are desperate to find out who they are. Increasingly, many of these people are finding answers and connecting with their biological families through DNA testing. My sympathies inevitably lie with them. The knowledge of one's identity is a fundamental human right and it is shocking that so many people today are still denied this most basic of all rights. I was struck by the disconnect between the donor-conceived people at the event and the people who are involved in the infertility industry. Clearly the change in the law was just the start of the process and there is much more that still needs to be done. Given that there is no legal requirement for the parents to disclose that a child has been adopted it seems that further legislation is likely to be the only way to guarantee the information that should be a child's right by birth.

BLOG ARCHIVE

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Ten years since the end of donor anonymity: have W...

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Further reading

- [A Storify of the event compiled by Bionews](#)
- [A report of the event for Bionews from Arit Udoh](#)
- [As consumer genomics databases well, more adoptees are finding their biological families](#) by Justin Web, *GenomeNews*, 25 September. Although this article is written from the perspective adoptees the same principles will apply to donor-conceived adults.

Resources


- [Donor Conceived Register](#)
- [Donor Sibling Link](#)
- The [Donor Conception Network](#) - an organisation set up to provide a supportive network for the parents of donor-conceived children and for donor-conceived adults.
- [DNA Detectives](#) - a Facebook group for genetic genealogists focused on finding biological family for adoptees, foundlings, donor-conceived individuals, unknown paternity and all other types of unknown parentage cases.
- [DNA testing for adoptees](#) - many of the resources listed are applicable for donor-conceived adults.
- [The Donor-Conceived DNA Project](#)
- [Human Fertilisation and Embryology Authority](#)
- [National Gamete Donation Trust](#)

Posted by [Debbie Kennett](#) at 11:15 p.m.  Labels: [Donor conception](#), [Sperm donation](#)

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Reactions: ☐ interesting (0) ☐ like (0)

1 comment:

**-rt_/)** said...
Thank you, Debbie, for posting this.
It seems immoral that the only persons without a choice in the process are the ones for whom the choices have the greatest consequences. We can't give them a choice at the outset, but we can give them full disclosure of information of importance to them.
[11 November 2015 at 18:01](#)

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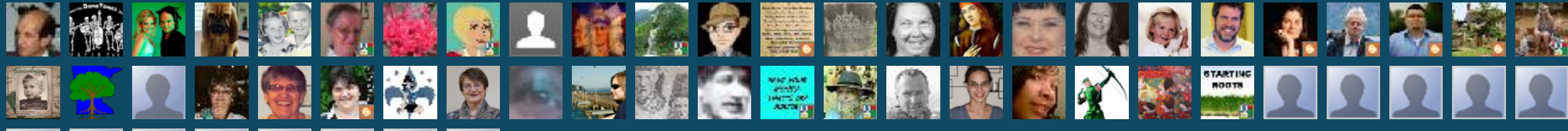
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