



Press release

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**Anonymous no more? Donor conception and direct-to-consumer genetic testing
#EndOfAnonymity**

Campaigning charity the Progress Educational Trust (PET), highlights tomorrow, at its free-to-attend #EndOfAnonymity debate, the need for increased awareness among the public and professionals that the advent of the genomic age means the anonymity of sperm, egg and embryo donors can no longer be guaranteed, and calls for appropriate support systems for everyone affected – donor-conceived individuals, donors and the families of both groups.

Sarah Norcross, director of PET, said: 'Ten years ago, at a PET meeting on sperm donation, PET trustee Professor Allan Pacey predicted home ancestry tests would be the end of donor anonymity. We are now in the genomic age with increasing numbers of donor-conceived children and their families uncovering their genetic origins both by design and by accident using home-testing kits. PET welcomes the recently-released UK guidelines on the use of donor sperm, eggs and embryos which recommend donors, recipients and their families should now be advised on the availability and implications of genetic ancestry testing and how donor anonymity is no longer guaranteed. This is a wake-up call for everyone involved in donor conception; there can be no more donor secrets. What is needed now is appropriate and adequate support for all affected.'

The #EndofAnonymity debate will hear from Debbie Kennett, genetic genealogist and honorary research associate at University College London, on the rapid growth of the genetic ancestry testing industry, how easy it is to find genetic relatives online in the big data era, and how many of the people taking the tests are doing so at a later stage of their life, in their 50s, 60s and 70s, often after receiving a home DNA kit as a birthday or Christmas gift. She said: 'We are seeing exponential growth of the direct-to-consumer genetic testing industry: in 2016, 3 million people had used these tests; in 2019, it's 30 million. One forecast suggests 100 million people will have used a home ancestry test by 2021. The genie is out of the bottle. Donor anonymity has ended; the question now is how do we deal with the consequences? For people who did not know they were donor-

conceived, their identity can be completely shattered; they feel like they have been lied to all their life.'

Andy Waters was a sperm donor in the UK before the law was changed to end anonymity and has been contacted in the last year by a number of his donor-conceived offspring, who found him after using DNA home-testing kits. He said: 'Donor anonymity is dead. The decisions parents make on whether, or not, to tell donor-conceived offspring about their origins are irrelevant. If we don't tell the donor-conceived their origins now, they will find out themselves; that's not if, but when. The popularity of genetic ancestry testing means it no longer matters whether you as an individual choose to join in, if your relatives do – your brother, your sister or your cousins, or even someone you share a great-grandparent with – genetic matches to you can be identified. Telling donor-conceived individuals earlier makes it much easier to assimilate and incorporate the information into their identity; the result of finding out later in life is typically distress, emotional harm, and anger towards the parents, who they perceive as lying to them. It is time to tell our kids where they come from, before they find out themselves, and hate us for it.'

Becky is a donor-conceived individual who is a member of a donor-conceived group who use genetic ancestry test to find out more about their biological origins and is increasingly being approached by half-siblings who have found her after using these home-DNA tests. She said: 'The increased use of genetic ancestry tests blows anonymity and secrecy out of the water, and this should be made clear to everyone involved. So much has changed in such a short time. The first time I was approached via a commercial DNA testing site by a genetic relative was about three years ago. Since then I have been contacted by eighteen people; fifteen of whom didn't know they were donor-conceived, for many their parents are dead and they can't get any answers – it's awful. This is now not about whether donor anonymity is helpful or not; donor anonymity is not possible, and everyone needs to be aware of that.'

Louise Johnson is chief executive of the Victorian Assisted Reproductive Treatment Authority (VARTA) which took the world-first decision, two years ago, to allow donor-conceived people to learn their donor's identity, regardless of whether or not the donor consented to this at the time of donation. She said: 'In Victoria, it's changed from being about whether to tell, to when to tell. There is a climate of openness; secrecy has been left far behind. There really is no guarantee of anonymity anymore; transparency and honesty are far more important. Young people, parents of donor-conceived children and donors are coming to us and are being linked up with genetic relatives via VARTA's central donor conception register and donor linking service. Even when donors had donated anonymously [prior to 1998], we are finding that the majority agree to provide information. But our research shows donor-conceived children want their parents, rather than anyone else, to tell them about their biological origins.'

The event will be chaired by Sarah Norcross, director of Progress Educational Trust and Dr Lucy Frith, reader in bioethics and social science at the University of Liverpool. ANONYMOUS NO MORE? DONOR CONCEPTION AND DIRECT-TO-CONSUMER GENETIC TESTING is at 18.30 on 19 June 2019 at University of Liverpool (London campus), 33 Finsbury Square, London EC2A 1AG. When covering this story, please mention PET and the Anonymous no more event, which is produced by PET in partnership with the University of Liverpool, with additional sponsorship from the European Sperm Bank and the London Women's Clinic. Register [here](#).

ENDS

Notes for editors

For interviews with participants and case studies, contact Catherine Hill, PET head of communications on 07305-091466 chill@progress.org.uk

1. A 2019 survey by [wearedonorconceived](#) revealed over a third of donor-conceived respondents (37%) discovered the truth about their biological origins from the results of a commercial DNA test such as 23andMe or AncestryDNA.

2. Recent [guidelines](#) from UK professional bodies on the use of donor sperm, eggs and embryos recommend: 'Clinical teams should provide support, guidance and information on the availability and implications of genetic ancestry testing, and the possible inevitability and lack of control over identity that an individual may have if a blood relation undergoes such testing. This applies to donors, recipients and their families.'

3. Anonymous sperm, egg or embryo donation is not permitted in the UK (donor anonymity was removed in 2005), although donor-conceived individuals can only request identifying information about their donor when they are 18. Individuals in the UK can still access anonymous donation via overseas fertility treatment.

4. *Removing donor anonymity retrospectively in Victoria, Australia – two years on*, a report by Louise Johnson, chief executive officer VARTA in [BioNews](#). In the first two years since retrospective donor anonymity was removed, 163 pre-1998 applications for information were made. Of these, 119 were made by donor-conceived people, seven by parents and 37 by donors. Of the 163 applications, 72 had known outcomes at the end of the second year. The remainder are still being processed. Of these known outcomes, 53 were applications for information about donors and 19 were applications from donors seeking information about their donor offspring. Of the 29 donors who were located, 21 agreed to be contacted, and eight lodged 'no contact' preferences.

5. The Progress Educational Trust (PET) is a UK charity working to advance public understanding of, and engagement with, science, law and ethics in the fields of human genetics, human reproduction, embryology and stem cell research. Funded by grants and public donations, PET aims to improve the choices for people affected by infertility or genetic conditions. <https://www.progress.org.uk/>

6. PET organises free-to-attend events debating the responsible application of reproductive and genetic science and publishes BioNews, a free comment and news service. Subscribe to BioNews at <https://www.bionews.org.uk/subscribe>

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