

# ConnecteDNA Research Project : Newsletter #2 December 2022

Welcome to our second newsletter – reporting our work and preliminary findings from the last 6 months.

## Interviews update – Dr Leah Gilman



### Interviews completed:

- Donors (18), donor conceived (DC) people (25), parents (20) – we are pleased to have achieved the numbers we hoped for. Thank you to all the individuals and organisations who have helped to spread the word about our research – and especially to those who have given us their time and reflections.
- We have also interviewed 2 donor relatives.

### Next steps:

- Although we have mostly stopped active recruitment of interview participants, we are still willing to interview people from under-represented groups – such as donors who would **not** welcome contact from their donor offspring, donor relatives and egg donors

### Key findings from the interviews – three challenges:

- **Being an intermediary or gatekeeper.** ‘Matches’ via DTCGT are rarely direct. The person in the middle often has to be the gatekeeper of secrets – which can be difficult.
- **Family dynamics after late disclosure.** The discovery of donor conception during adulthood often has profound implications for people’s sense of identity and be really disruptive to their family relationships
- **Dilemmas around early testing of children.** A significant minority of parents we interviewed had young children (around 2) and were considering using DTCGT to test them whilst they were still young. Others considered that testing children before they could have a meaningful say in the decision, was controversial. Weighing up the issues involved is challenging.

## A message from Dr Lucy Frith, PI



Thank you very much to everyone who has supported our research over the last six months. We have both been continuing our data collection, and disseminating our early findings. We hope the snapshots in this newsletter provide an interesting flavour of this work.

## Socio-legal work update – Dr Caroline Redhead



### Law in the UK and elsewhere – how do they compare?

#### Donor anonymity

- Sweden - banned from 1985 (prospective)
- Netherlands - banned from 2004 (retrospective with consent)
- Victoria, Australia - full retrospective release of donor information 2016 and contact preference system – from 2017
- UK- banned from 2005 (donors can re-register to consent to information release)

#### At what age can children access information?

- Sweden - 18 (identifying), younger with consent
- Netherlands - 12 (non-identifying) and 16 (identifying)
- Victoria, Oz – at any age with parental consent or without consent if accept counselling and deemed ‘sufficiently mature’
- UK- 16 (non-identifying) and 18 (identifying)

#### Access to DTCGT for children?

- Varies, typically 13 for some services, usually 18+ for online DBA testing
- But how is it enforced? Nb the role of parental choice (see interview findings)

#### Challenges for the law:

- How should information be shared and managed as between donors and any children born of their donation? What represents the best balancing of the interests of both groups – especially where the donation was given under conditions of anonymity?
- At what age should children have access to that information? Should parents have access to it before their children?
- Should parents be obliged to tell their children about their DC status? At what age? What about enforcement of that obligation?
- What is the role of the state (eg through birth registration) in managing DC people’s access to information about their genetic heritage?



# ConnecteDNA stakeholder workshops

## Preliminary findings

We hosted two stakeholder workshops in November, 2022. They took place in Manchester (on 2<sup>nd</sup> November) and London (29<sup>th</sup> November). A total of 30 people participated, representing the perspectives of donor-conceived people, donors, parents by donor-conception, counsellors and clinic staff. **Our final workshop will take place in Birmingham on 25<sup>th</sup> January. Join us, if you can!**

Our hope was to energise some discussion – and we were not disappointed! Participants were fully engaged in the questions we asked - we could have talked for many more hours than were available to us. We are very grateful to everyone for their enthusiasm.



### Timeline exercise for planning support

We discussed the challenges donors, parents and DC people might experience over their life course and how our research could support them. Suggestions included:

- Supporting parents to talk to their DC children about their conception.
- Supporting donors to talk to their partners, (non DC) children and wider families about donation.
- Raising awareness of the different possibilities for contact between donor relatives, inc. 'official' and 'unofficial' routes.
- Increasing public knowledge and understanding of DC and the stories of DC people & families.

### Legal 'world café' discussion

- **The role of the law in online DNA testing?** Duty of care; better information BUT providers are being blamed for social norms
- **How could/should the law support service users?** Require education/information + signposting to support services
- **Legal change in the UK around donor anonymity?** Normalise all paths to parenthood – but mixed views about removing anonymity. Transparent birth certification important
- **What age for children's access to 'official' information sources?** A variety of views – but child's welfare is the key concern. General feeling that earlier disclosure less harmful

