

Case Studies:

Examples of how online DNA testing is being used by the UK donor conceived community

The following case studies come from the research conducted as part of the ConnecteDNA Research Project. They are intended to provide some examples of how DNA testing is being used by those impacted by donor conception in the UK, and to understand some of the implications of this technology for those affected by donor conception.

A note on language: lots of the terminology around donor conception and the different parties involved is contested. In these case studies, the range of terms used reflects the varied language used by those we interviewed for the project. We recognise that this will not reflect the language choices of all donor-conceived people or others impacted by donor conception.



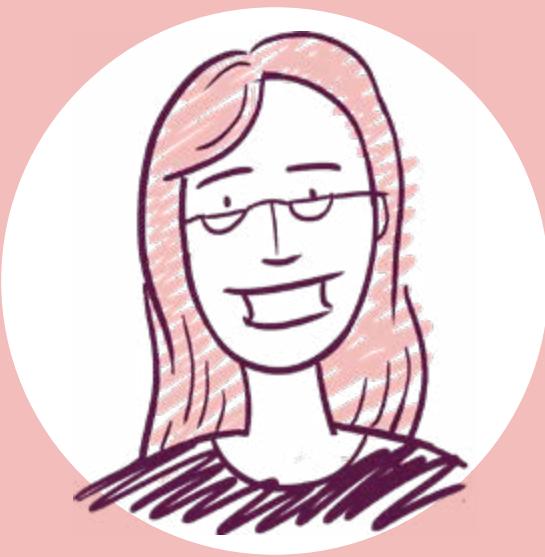
DNA testing in families where people knew they were donor conceived

Increasingly, donor conceived children grow up knowing that they were born as a result of donor conception. In these families, online DNA testing can be understood as a useful tool for the family to learn more about the donor and to connect with donor siblings. Parents may find it helpful to gain information about donor relatives which can help them to answer their children's questions.

Ellie:

Ellie grew up with two Mums and described always knowing that she was donor conceived. For her, the decision to use an online DNA site in her early 20s was driven by curiosity. After some time, and with support of a family member who undertook some 'detective work' on her behalf, Ellie matched with a relative of the donor. Ellie told the donor's relative her story, explaining that she thought someone in her family had been a sperm donor. Following a few months of silence, the relative got back in touch telling Ellie that the match had taken a test himself and was the donor. Ellie now has a 'nice' relationship with the donor; they have met up several times and regularly chat over video call.

It is important to know that while online DNA testing may be a useful tool for many, finding close matches (either quickly, or at all) is not guaranteed – and that even when 'matches' are discovered this may not always lead to contact or a relationship. It is useful to think about how you/your child may feel if you do not find any information about the donor/donor siblings, and what support you may wish to access to cope with this.



Zoe:

Zoe grew up knowing that she was donor conceived. When she was 16, her Mums bought her an online DNA testing kit as a gift. She was a little disappointed to find no close matches to donor relatives but is aware that she may get some matches in the future when her donor siblings are older.

As Zoe's story indicates, it is also important to remember that new matches may be found over the months and years as new people upload their data to the online DNA testing sites. Some people find this emotionally challenging or draining, so it is worth thinking about how you will manage your personal boundaries and what support you may be able to access during this time (such as speaking to a trusted friend or family member, peer support networks, or counselling services).

Beth:

Beth found out she was donor conceived when she was thirteen. A number of experiences throughout her late teens and early twenties confirmed to her that she did want to trace donor relatives, and so after exploring a few other avenues she decided to do an online DNA test. Initially her only match was a distant cousin, but after about six months she found an email in her junk folder to say she had received a message from another user - who turned out to be her genetic half-sister. After a few years, Beth decided she wanted to take more active steps to find her 'bio dad' (as she calls him), and managed to do so through a combination of DNA site matching and social media. Although she has positive relationships with both her half sister and her 'bio dad', Beth is no longer actively looking for matches as she finds the process emotionally exhausting. Indeed, she now experiences a sense of relief when she logs onto the online DNA sites and finds no new matches.



DNA testing when someone did not know they were donor conceived

People have many reasons for submitting their DNA to an online testing company, and this gives rise to the potential for unexpected discoveries of donor conceived status. Many are shocked to find out that they are donor conceived, as John's story illustrates:

John:

John found out he was donor conceived in his late 30s, as his wife ended up with a spare 23andMe test. He did not expect to find out anything serious but thought it would be a fun and interesting thing to do. He was completely shocked to discover a man who shared 50% of his DNA described as his father in the relative finder section. His first thought was that his mother must have had an affair, but this did not fit with her character. He immediately messaged this person via the site, looking for answers, and the relative replied explaining that he had been a donor. John has established a good relationship with his genetic father, and has met up with him occasionally. Finding out this news has helped him to make sense of feelings of not belonging and confusion about lack of family resemblance which he remembered experiencing at earlier points in his life.

With these unexpected discoveries it is not uncommon for it to take a bit of time for people to understand the results:

Yvette:

Yvette took an online DNA test to see whether she had any Scandinavian ancestry. The results came back early one evening while she was watching TV with her husband and children. Opening the email, she saw that one result indicated a parent-child relationship between her and a man who she did not know. Yvette was shocked. She looked at his image and saw a clear facial resemblance. Her initial thought was 'oh my god, my mum had an affair'. Aware that she had to get through the rest of the evening with her family, Yvette said nothing until after the family had eaten dinner. Only then did she tell her husband. Slowly, as the initial shock passed, she began thinking 'logically' about the situation. She knew that her parents had taken more than five years to conceive her and it occurred to her that it was more likely they had used donor sperm, than that her mum had an affair. However, she found not knowing for sure very stressful. She contacted the donor through the online DNA testing site Ancestry, and he confirmed that he had been a sperm donor - which she found reassuring.

Fiona:

As a result of infertility, Fiona and her husband used donor sperm to have children. When one of their children indicated an interest in knowing more about her genetic father, Fiona decided she would also take a DNA test so that it would be easier to identify whether any connections they discovered were on the donor's side. Fiona was confused and shocked when the online DNA testing site identified a match between herself and a man, who was originally identified as her cousin but who she now understands is her half-brother. Though initially denying that there was anything unusual about Fiona's conception, her mother eventually admitted that Fiona was conceived using donor sperm. However, this did not bring the secret fully into the open; Fiona's Mum made clear she would not speak about the situation any further and asked that Fiona not tell her Dad, who was quite frail, that she knew. Fiona and her parents have always been close, but this has put a strain on their relationship. Fiona traced her genetic father and has met up with him once. However, his family do not wish for him to have a relationship with Fiona – and indeed he had to 'sneak out' to meet her. Fiona does not expect that they will see each other again.

As Fiona's story demonstrates, managing to trace the donor does not guarantee that a person will develop a meaningful relationship with them. In some cases, the donor may already be deceased by the time they are traced – though as Nick's case demonstrates this does not necessarily mean that nothing positive can come from identifying the donor:

Nick:

Nick found out that he was donor conceived when he was in his 30s. Once he found out, he began to try and trace the donor – uploading his DNA data to a number of websites. He initially managed to trace a great aunt, and contacted her by email. Her son, who was managing the account on her behalf, contacted Nick and suggested that they talk. After Nick explained the situation and sent a photograph of himself to his great aunt's son, the man identified one of his cousins as Nick's genetic father. However, he explained that Nick's genetic father had sadly died in his twenties, not long after Nick was born. Nick feels sad that he will never meet him. However, he is really pleased that his genetic father's wider family have been really welcoming to him, and feels that to some extent he has got to know his genetic father through them.

Online DNA testing can also give rise to situations where donor conceived people themselves become 'gatekeepers' of information. This can add an extra layer of complexity at an already emotional time:

Harris:

Harris found out he was donor conceived when he was in his early twenties when he did an online DNA test and matched with a half sibling. He messaged her and found out she was equally shocked at their match! He then spoke to his Mum, who explained that he was donor conceived as his Dad had been unable to have genetic children. Harris found this revelation very upsetting, and he cried for a long time the night he found out. He had not had a good relationship with the man he had previously believed to be his genetic Dad and had had limited contact with him. He felt as though he had wasted many years mourning a poor relationship with a man whom he had believed to be his genetic father.

Harris decided to upload his data to other DNA matching services. He matched with three further half siblings and in each of these situations he found himself in the position of having to tell the matches that they were donor conceived. Harris took care to do this sensitively, providing his own story and allowing his donor siblings to join the dots of what this meant for them. This was challenging in one case, as one of his donor siblings did not wish to accept that her sadly deceased father was not her genetic father.



A donor's perspective on online DNA testing

Many donors who make themselves available through online DNA tests express an intention that should a match occur, they would let the donor conceived person lead the process of making contact and decide what that contact would look like. This is illustrated in Kylie's story:

Kylie:

Kylie is an identity release egg donor, who believes that the children born from her donation have a right to contact her if they desire. She plans to do an online DNA test in the future, in order to give the people conceived from her donation another way to contact her, should she forget to update her address or should they simply prefer an alternative to the 'official' route. While she intends to take a test and make her information available, she does not intend to 'go looking' for those born through her donation. Should there be a match, she expressed an intention to take a step back and allow the donor conceived person to shape the interaction (including allowing them a choice of whether or not any contact takes place. Though she did not object to being contacted by a teenager under the age of 18, she feels that she would ask to speak to their parents before having further interaction.

Kylie's story highlights the possibility that a donor conceived person may take an online DNA test and reach out before they are eighteen – that is to say, prior to the age at which they can access identifying information through the HFEA. It is important to recognise that some donors may feel differently about having contact with a child than they would about having contact after the child has turned eighteen.

Sometimes, those who have donated sperm or eggs have not told any, or all, of their family members that they have done so. This is not necessarily a barrier to establishing contact and a relationship with children conceived through their donation, but it can make the process more complex for them. Mickey's story reflects this complexity:

Mickey:

Mickey had donated sperm in his early 20's in order to earn some extra money. He later married and had two children of his own. While his wife and many of his friends knew he had been a sperm donor, his own children did not. Around 30 years after his first donation, he was contacted by a first cousin who asked if he had ever donated sperm, explaining that she had been contacted via 23andMe by Sarah who was looking to trace her donor. At his cousin's suggestion, he took an online DNA test to confirm he was Sarah's genetic father: which it did. The pair have been in touch regularly and built a relationship which he really values. Through Sarah he has also been in touch with two others conceived from his donation. He has really enjoyed developing these relationships and considers the children born through his donations as part of this family. However, at the time Sarah contacted him he was going through a divorce and was mindful of the emotional impact this had on his children, especially his youngest daughter. Though he plans to tell his children about the relationship with Sarah as it seems likely to be lasting and significant, he is worried that his children could feel excluded or rejected by this new relationship.

Resources

We hope you have found these case studies useful, please see our project website for more information about our publications and outputs.

To find out more about the ConnecteDNA project:
<https://sites.manchester.ac.uk/connecte-d-n-a/>

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