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Fiom KID-DNA Databank's fifth anniversary

EXPERIENCES IN MATCHING SPERM DONORS AND DONOR CONCEIVED CHILDREN

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Abstract

Before the *Wet Donorgegevens Kunstmatige Bevruchting* (Dutch law on artificial-insemination donor data) was introduced in 2004, about 40,000 donor-conceived children were born in The Netherlands. The majority of these children were conceived through artificial insemination using anonymous donor semen (AID or KID in Dutch). These donor-conceived children have little or no access to information about their origins due to these anonymous donations. Donor-conceived children and donors can be linked to each other via Fiom's KID-DNA Databank, which was started in 2010 in cooperation with the Canisius Wilhelmina Hospital. Donor-conceived children, donors and half-siblings can be matched through DNA profiles. We expect the number of donor-related searches to rise over the next few years. In this article we would like to report our experiences in matching and counseling donor-conceived children and donors. These experiences have been very helpful for donor-conceived children and donors who are in search for each other. Moreover, they provide a tool for building meaningful mutual relationships.

In the Netherlands, children conceived with the aid of donor sperm, donor oocytes or donor embryos have the right to know their donor's identity as soon as they reach the age of 16, according to the law on artificial-insemination donor data, which came into effect in the Netherlands in 2004.^{1,2} From then on, donor data must be registered at *Stichting Donorgegevens Kunstmatige Bevruchting* (SDKB; foundation for donor information in case of artificial insemination). We estimate that, up to 2004 about 40,000 donor-conceived children were born,³ the majority of which were conceived by artificial insemination with anonymous donor sperm (AID). This means that these donor-conceived children have little or no access to information on their descent.

Questions about searches that come in at *Stichting Fiom*, a knowledge centre for questions related to people's descent and enquiries gathered from interest groups show that a number of these donor-conceived children are in search of their biological family. However, the size of the group of potential searchers is unknown. An explanation for this fact is that, among other things, up to 2004, donor conception was surrounded with secrecy

and donor-conceived children do not always know about their descent. In addition, feelings of loyalty towards their parents may influence the search.

International studies show that 80-83% of the donor-conceived children interviewed start a search for information or contact with their donor.^{4,5} Just like the findings of this article, the results of these studies only relate to donor-conceived children who are aware of their origins and who know that there are options available to go and find their biological family. It is therefore a selective group, which can not be generalized to the total population of donor conceived children.

As a specialist in the field of family searches, KID-DNA, foundlings and surrogacy, Fiom knows how important it is for people to get to know their genetic background. That's why Fiom's KID-DNA Databank was established in 2010, in cooperation with the Canisius Wilhelmina Hospital (CWZ) in Nijmegen, the Netherlands. In this article we would like to share the practical experience we have gained in the past 5 years in matching and counseling donor-conceived children and donors who are in search of their biological family and are using Fiom's KID-DNA Databank to achieve this. The reported data come from information obtained through registrations, questionnaires and conversations.

Fiom's KID-DNA Databank

Besides the UK Donor Conceived Register, Fiom's KID-DNA Databank is the only databank in the world that uses DNA profiles when matching donors and children who were conceived through AID.⁶ Thanks to DNA matching, donor-conceived children, donors and half-siblings can be linked. Sometimes, additional research is needed, such as a DNA profile of a biological mother in order to confirm a match of donor-conceived children, donors and half-siblings.

There is a need for matching with the help of DNA profiles, because registration information from before 2004 may not be complete or correct. In 2015, there was much commotion when it became clear that the Medisch Centrum Bijdorp sperm bank did not have a reliable registration procedure in place, even after 2004. This resulted into cases where children who were conceived through this clinic - which has been closed in the meantime - were not able to trace their donor. For this group of donor-conceived children a DNA test is also indicated when they want to meet their donor.⁷

At the end of the first 5 years, 786 people were registered with Fiom's KID-DNA Databank (figure). About two thirds of the people registered are donor-conceived children; others are donors (30%) and mothers (7%). During this five-year period, 129 people were matched to another registered person, whose kinship was confirmed. The table gives an overview of the matches.

FIGURE 1: Number of registrations with Fiom’s KID DNA Databank on 31 December 2015

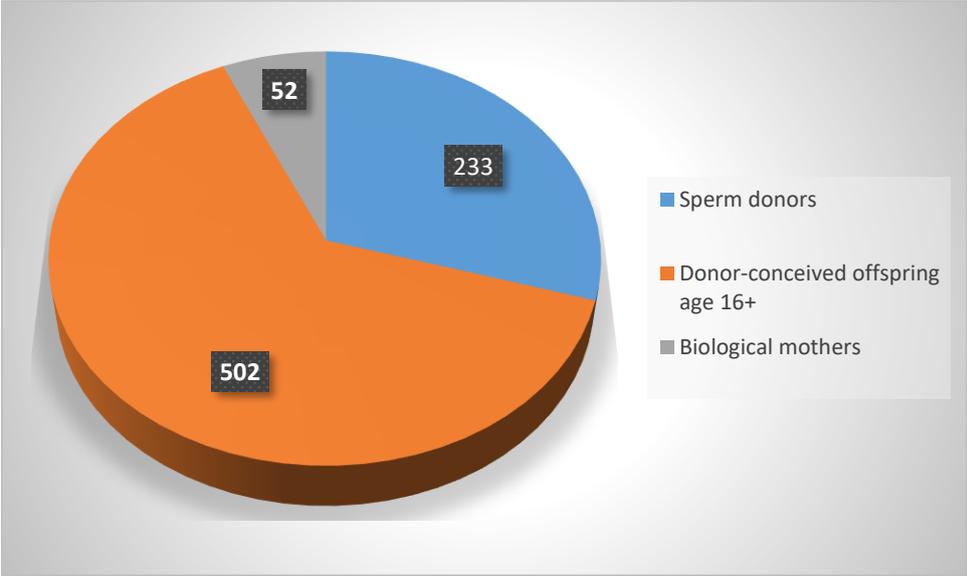


TABLE 1: Number of matches of people registered with Fiom’s KID DNA Databank*

Match of donor and donor-conceived child	Match of donor-conceived siblings
23 donors and 1 donor-conceived child	30 donor-conceived children and 1 half-sibling
6 donors and 2 donor-conceived children	3 donor-conceived children and 2 half-siblings
3 donors and 3 donor-conceived children	5 donor-conceived children and 4 half-siblings
1 donor and 14 donor-conceived children	

Note:

* These matches have taken place during a 5-year period, involving 33 sperm donors and 96 donor-conceived children.

The meeting of a donor-conceived child and a donor

The questions that were asked to the donor by donor-conceived children when they met were about the motivation to donate, the donor’s character, his medical background and the donor’s family. One thing that kept recurring during meetings was that they compared their looks, interests, preferences (for food for example), skills (such as making music or painting), and the disposition for learning languages or science subjects.

A meeting can be very emotional, even afterwards. Sometimes, expectations are not met and feelings of loyalty towards their parents also play a role in the donor-conceived child’s decisions. Donor-conceived children aged 16 to 18 often need an answer to factual questions (motivation, family, interests). After having received this information, their needs have been fulfilled, or at least temporarily. Older donor-conceived children prefer to have

contact with the donor and they see him as a source of information about themselves, their health and their origins. In this period in their lives donor-conceived children are usually busy with their jobs, education and families. Anticipating on new relationships with next-of-kin requires a lot of effort: literally from making time to organize actual meetings to all that is needed to define and build these new relationships.

Profile donor-conceived child

On 31 December 2015 there were 146 (28.9%) male and 356 (71.1%) female donor-conceived children registered in the Fiom KID-DNA Databank. They had an average age of 29 years (range 16 – 60 years). Almost half of the donor-conceived children in the database were informed about the donor conception at the age of 17 years or older. A third of the them knows about their origins since early childhood (0-6 years). Over two thirds of these children have signed up because they are curious and think they have a right to know from whom they descent. They want information about the donor and seek recognition. There are also donor-conceived children who indicate that they experienced a loss, others are just looking for medical information. Almost all of these children are supported by their parents in the search for their lineage information.

Abolishing donors' anonymity

Although donors donated sperm in the past in an anonymous way, the ones who register in the databank have chosen to become identifiable. They agree to the fact that children who were conceived with their donor semen, have the right to ask questions. Besides, they are interested as well in information about, or contact or a meeting with their donor-conceived offspring. Another reason for registering may also be to provide medical information.

Partners of donors are often aware of the donations, while more than half of the children in donors' families do not know it (yet). Registering in the databank triggers a sense of openness in the donor's family, especially when there have been successful matches. After a match, it is possible that a donor-conceived child also want to contact the family of the donor. Nevertheless, there are partners and children of donors who are having a hard time when they are faced with donor children. They struggle with the question whether the existence of a donor child can be adjusted into the core family or extended family.

Profile donor

The average age of the sperm donor registered in the Fiom KID-DNA Databank is 63 years (range 42 – 90 years). Most donors have donated anonymously before 2004 and have made more than 20 donations.

Multiple donor-conceived children

Although the Board of Health stated in 2013 that no more than 25 children could be conceived per sperm donor,⁸⁹ the number may be higher in practice, as this maximum was

not legally adopted. Moreover, a central registration of both the number of donations and the number of donor-conceived children is lacking, which results into the fact that the maximum standard cannot be monitored. Donors therefore do not know how many children were born from their donations and are not able to estimate the number of future requests and the extent of the emotional burden this will entail.

There are older donors and family members of donors who say they find it difficult when they – in the long run – are linked to multiple donor-conceived children; they are experiencing or expect to experience a point of saturation. The willingness to meet donor-conceived offspring following a number of meetings declines, which means that donor-conceived children who have been matched at a later date, do not have the opportunity any more to get to know their donor. Fiom is going to ask donors to create a video recording in which they can introduce themselves, so that these children will be able to get to know their donor up to a certain extent. Such a video recording can also be a solution when a donor is too sick to be able to meet the donor-conceived children.

Fiom's support

Fiom offers support to donor-conceived children and donors who have registered in the databank and at the request of the SDKB Foundation. In case of a match we get in touch with the people involved. During the first conversation we talk about desires and expectations regarding contact options, among other things. Whether there will be a meeting and identifying information will be given depends on the wishes of donor and donor-conceived child.

A first meeting is the start of a new chapter in the lives of donor-conceived children, donors and their families. Defining the new relationships takes time, including breaking through secrecy when the donor conception and donor ship in the direct environment of the donor-conceived child or the donor was kept a secret. Meetings with half siblings seem to be less tense. This may have to do with the fact that they have about the same age and history, but also because there is no conflict of loyalty towards their parents. Not a lot of research has been done into half-siblings of donor-conceived children.¹⁰ In order to gain insight into the impact of a successful match, it is recommended to further investigate the half-siblings aspect.

After the meeting the social worker has contact with the people involved on 2 to 5 occasions. The meeting is reviewed and attention is being paid to further build the mutual contact. The social worker also explores any further needs for assistance. Concluding the aftercare leads to the temporary closing of the client's file. Should there be a new match concerning the person involved, the file will be reopened.

What will the future hold?

More and more people find their way to Fiom's KID-DNA Databank. This is a positive thing. The more donors and donor-conceived children are having their DNA profiles stored, the

bigger the chance for a match of donors and donor-conceived children and among donor-conceived children.

Social workers are increasingly faced with the effects of 'individual' searches, via social media for example. There have been cases in which donor-conceived children are convinced to have found their donor. They have had contact and they are sure they are related based on the contact. When a DNA test reveals that the supposed match is incorrect, this results in a great disappointment.

Today, donor conception is not so much surrounded by secrecy anymore as before 2004. Parents and professionals acknowledge that informing children early on in life about their origins is a good thing for all those involved.¹⁰ It is to be expected that the number of children that were informed at a young age will increase. Nevertheless, parents may struggle finding the right words to tell the child about the story of their origin.¹¹

After the Dutch law on artificial-insemination donor data came into effect, at least 6000 children were registered in the Netherlands who were born using a sperm donation in de period 2004-2013.¹² When these children reach the age of 16, so from 2020 onwards, they will be able to contact their donor and their half siblings.

Conclusion

The past 5 years, Fiom has helped donor-conceived children and sperm donors in finding and meeting each other through Fiom's KID-DNA Databank. They have received an answer to questions that were very important to them and they were able to contact their donor and half siblings. The knowledge we have gained from this is now helping other donor-conceived children and donors who are still searching and it offers a tool for building a meaningful mutual relationship. These experiences will also be used for children who have been registered since 2004 with the *Stichting donorgegevens kunstmatige bevruchting* and who may want to contact their donor and their half siblings from 2020 onwards.

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