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**Anonymous Dutch sperm donors releasing their identity**

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# **Anonymous Dutch sperm donors releasing their identity**

## **ABSTRACT**

This study examined the motivations of anonymous Dutch sperm donors to release their identity. It aimed to increase knowledge and encourage donors to become identifiable through a more informed decision, allowing more donor-conceived persons to contact their donors. Since 2010, anonymous sperm donors can register in the Fiom KID-DNA Database developed by Fiom and Canisius Wilhelmina Hospital (CWZ). An online survey was sent to donors who registered in the database (May 2015-August 2017). A total of 179 male respondents participated in this study. The motives of most donors to register in the database were child-oriented: donors believe that their offspring are entitled to their physical and social details and/or they want to give their offspring the chance to contact them. Other motives are donor-oriented, such as the curiosity about the number of offspring, their well-being and the desire to establish contact. This research showed that, to encourage anonymous donors to release their identity, one should focus on providing information about the existence of DNA databases. As well as increasing the donor's awareness of problems donor-conceived persons can experience by the lack of knowledge about their descent, answering questions and concerns from donors, and exploring the curiosity about their offspring.

**KEYWORDS:** sperm donation; donor insemination; open-identity donors; anonymous donors; motivation; DNA registers.

## **Introduction**

Sweden was the first country to abolish donor anonymity in 1985 (A. Lalos, Daniels, Gottlieb, & Lalos, 2003). In 2004, almost twenty years later, the Netherlands passed the Information Donor Insemination Law (Wet Donorgegevens Kunstmatige Bevruchting) (Janssens, Simons, Van Kooij, Blokzijl, & Dunselman, 2006). This law states that persons who were conceived as a result of donor insemination (in Dutch called KID) from 2004 and onwards are entitled to information about their descent.

Before June 2004 most donors donated anonymously. Information about them (such as donor registration number or number of donations) was often incomplete or missing. This lack or incorrectness of information about the donors' identity was sometimes also found in files from donors who opted for non-anonymity, which was an option from 1989-2004 (Visser et al., 2016). In the Netherlands, an estimated 40.000 persons were conceived by donor insemination before the use of open-identity donors. These persons have limited or no access to identifying information about their donor.

Fiom, a national organization that provides independent information and support in the search for biological origin since 1930, wanted to help. The Fiom website (<https://fiom.nl/>) offers information on donor conception to all those directly involved, provides access to DNA-based searches and offers personal stories and information from donors, donor-conceived persons and parents. To enable donor-conceived persons to get information about the donor, the Fiom KID-DNA Database was developed in 2010 in collaboration with the Canisius Wilhelmina Hospital (CWZ). This voluntary DNA-database allows donor-conceived persons and donors donating prior to 2004 to register and send in their DNA (Crawshaw et al., 2015). Fiom mediates contact between donor offspring and allows donors and donor offspring to receive counselling for themselves and their family.

Previous studies showed that donors who donated anonymously in the past do not necessarily want to remain anonymous in the future (Bay, Larsen, Kesmodel, & Ingerslev, 2014; Daniels, Blyth, Crawshaw, & Curson, 2005; Jadv, Freeman, Kramer, & Golombok, 2011; Robinson et al., 1991; Thorn, Katzorke, & Daniels, 2008). In June 2017, the Dutch Minister of Health, Welfare and Sports, made a public appeal to anonymous donors to ‘perform a second good deed’ by registering their DNA in the Fiom KID-DNA Database. The appeal was part of an action plan that was created by the ministry in co-operation with interest groups to support donor-conceived persons who wish to have access to information about their descent. In the appeal, the minister emphasized the importance of having access to this information because a lack of knowledge can have an incredible impact on the life of the donor-conceived person. In addition, she removed the registration fee, giving donors the opportunity to register free of charge in the Fiom KID-DNA Database (Schippers, 2017).

The current study examined the motivation of anonymous Dutch sperm donors to release their identity. It aimed to increase knowledge and encourage donors to become identifiable through a more informed decision, allowing more donor-conceived persons to contact their donor.

There are only two registers in the world that use a DNA-based approach that has been specifically developed to enable counseled contact between donor-conceived persons and their donor. The UK DonorLink (UKDL) was established in the United Kingdom in 2004 and transferred to the Donor-Conceived Register (DCR) in 2013 (Blyth, Crawshaw, Frith, & van den Akker, 2017; van den Akker, Crawshaw, Blyth, & Frith, 2015). The Fiom KID-DNA Database was established in the Netherlands in 2010. In July 2018, 91 donors were registered in the UKDL (verification via personal communication DCR) and 534 donors were registered in the Fiom KID-DNA Database.

Researchers have found relationships between the willingness to be identifiable and specific demographic characteristics of donors, but their findings were ambivalent (Van den Broeck et al., 2013). Thijssen et al. (2017) showed in a study among anonymous Belgian donors that men who had child(ren) 'of their own' were less willing to release their identity or contact their donor offspring. However, these findings were not in line with the results from Thorn et al. (2008), who found that among German anonymous donors that 'having children of their own' was not a relevant factor that influenced their attitudes towards openness. Furthermore, the findings contradict the study of Daniels et al. (2005) who found that UK anonymous donors claimed that the experience of raising their own children had motivated them towards more openness.

Thijssen et al. (2017) stated that men who have a partner are less willing to release their identity. These findings were in line with the results of Riggs and Russell (2011) who discovered that a larger proportion of men in relationships (ages 26-45) remain anonymous and that men in heterosexual relationships would be less likely to release their identity than men of the same sex. The older German anonymous donors in the study of Thorn et al. (2008) tended to have a more open attitude. Sydsjö et al. (2012) showed that since the exclusive use of open-identity donors in Sweden there was a shift in the profile of sperm donors to more mature individuals.

A few studies have examined the motivation of anonymous donors to become identifiable. In the study of Blyth et al. (2017) among 21 sperm donors registered in the UKDL, various reasons of enrolment in a DNA-based register were indicated. Firstly, donors wished to assist donor-conceived persons who were seeking information about their genetic origin. Secondly, donors wanted to inform their own children about the possibility that they are genetically linked to others through the sperm donation of their

father. Thirdly, donors indicated their need for information and contact with their donor offspring.

Daniels et al. (2005) examined the willingness of anonymous donors to become identifiable in the future. Reasons given by donors to step out of anonymity were: experience as a parent, getting older, media attention, greater awareness of implications of donor conception and the needs of offspring, general life experience, and the view that offspring have the right to know. The anonymous donors in the study of Jadva et al. (2011) who were willing to make contact, or had already done so, gave the following reasons: understanding consequences of donation that they had not fully comprehended at the time of donation, feeling the moral obligation to provide information to their offspring, the view that they are entitled to obtain information if they wish, the desire to learn about the experiences of donor-conceived persons, and the importance for people to have access to medical information.

Men who donated in the Netherlands before 2004 are often not informed about the number of children conceived by their sperm. This lack of information can be a barrier for donors to release their identity. However, through a government directive the maximum number of children per donor has been set at 25 (Gezondheidsraad, 2013), this number is not fixed because it is not legally established (Postema & Maas, 2017). In 2017, there was a lot of media coverage in the Dutch national press about donor-conceived persons who were faced with problems due to previous shortcomings, abuse and mismanagement of sperm banks. Donor-conceived persons and their parents were disappointed and angry about the course of events (e.g. the fact that a doctor used his own sperm when inseminating patients) (Baard & Van der Mee, 2017), the shortcomings in the registrations of fertility clinics (Nagtegaal, 2016), and the absence

of supervision and registration on the maximum number of children per donor (Kreulen, 2017; Van der Wiel, 2017).

For those donors who want to remain anonymous, medical and technological developments may endanger their anonymity. Today internet, social media, donor registers and international genetic databases affect people's privacy. So far (dated January 2017), more than 17 million people have used genetic testing to find information about their origin (Janzen, 2018: [https://isogg.org/wiki/Autosomal\\_DNA\\_testing\\_comparison\\_chart](https://isogg.org/wiki/Autosomal_DNA_testing_comparison_chart)). Many of them subscribe to donor registers, such as the Donor Sibling Registry or the Central Register of VARTA, and/or international genetic genealogy databases, such as Family Tree DNA, Ancestry, 23andme and Gedmatch (<https://www.familytreedna.com>; <https://www.ancestry.com/>; <https://www.23andme.com/>; <https://www.gedmatch.com/login1.php>), to encounter relatives. A situation has now arisen in which donor anonymity does not exist anymore (Pacey, 2018). People who have not asked for it (or who do not want to be found) can be traced without knowing it because the DNA of a relative is submitted to these databases. Furthermore, people may unintentionally discover that they were conceived via donor conception (Harper, Kennett, & Reisel, 2016; Crawshaw, 2018).

## **Materials and methods**

This study was conducted in accordance with the principles of the Helsinki Declaration. From May 2015 to August 2017, donors ( $n=244$ ) were asked during the registration process whether they were willing to fill in a questionnaire for research purposes. Subsequently, they were asked to leave an email address to which the survey was sent.

Donors who registered before 2015 ( $n=203$ ) could not be approached due to privacy legislation.

Respondents were asked about their socio-demographic characteristics and their motivation to register in the Fiom KID-DNA Database. To enable a closer analysis of the motivations to register, respondents were presented with a list of seven motivations and the open category 'other'. The items (seven motivations) were compiled from information retrieved from the clinical experiences of the Fiom social workers who were counselling the donors who had a DNA match with a donor-conceived person in the Fiom KID-DNA Database. Respondents were able to select multiple answers or answered the question by defining another motivation in the open-question section 'other'. Multiple response analysis was used to analyse the frequency when there can be more than one response per respondent to a survey question (Grotenhuis & Matthijssen, 2005).

The survey data were entered online through the web content management system (CMS) Drupal and the rough data were uploaded to an Excel data file and verified for consistency. Subsequently, the Excel data file was exported to the software program SPSS version 24, for statistical analysis. SPSS was used to analyse all motivations together and to determine a multiple response variable. The various motivations given in the open question-section 'other' were coded into categories, from which five additional variables were constructed (Table 2).

Table 1. Characteristics of donors and their donations

<b>(a) age of donors who decide to release their identity</b>				
	<i>n</i>	%		
Under 36 years	2	1.1		
36-50 years	17	9.5		
51-65 years	97	54.2		
66 years or over	63	35.2		
<b>(b) Estimated period of donations per donor</b>				
	<i>n</i>	%		
1960s	1	0.6		
1970s	43	26.1		
1980s	70	42.4		
1990s	38	23.0		
2000s	13	7.9		
<b>(c) donor's own children</b>				
<b>Number of children</b>	<b>Number of donors during donation</b>	<b>%</b>	<b>Current number of donors</b>	<b>%</b>
0	78	47.6	32	19.2
1	15	9.1	21	12.6
2	45	27.4	60	35.9
3	13	7.9	35	21.0
4	11	6.7	14	8.4
5	1	0.6	1	0.6
6	1	0.6	3	1.8
7	0	0	1	0.6

## **Results**

### *Database*

By the end of August 2017, 447 donors and 921 donor-conceived persons had registered with the Fiom KID-DNA Database. A significant proportion of donors (21.5%,  $n=96$ ), had registered in the three months after the Minister of Health, Welfare and Sport made a public appeal (in early June 2017) to donors to make themselves known. During the period of May 2015 to August 2017, a total of 244 donors registered with the Fiom KID-DNA Database. Of these, 179 completed and returned the questionnaire: a response rate of 73% ( $n=179$ ).

### *Demographic characteristics of donors*

The median age of the respondents was 63 years (range 35 to 78). Most men (89.4%,  $n=160$ ) were over fifty years old (Table 1). They were born in the Netherlands (86.8%,  $n=155$ ) and a few in Belgium (3.9%,  $n=7$ ). Other countries of birth (mentioned once) were Brazil, Canada, Indonesia, Malaysia, Surinam and Sweden. During the period of donation, more than half the donors had children themselves (52.3%,  $n=86$ ) and at the time of registering in the Fiom KID-DNA database, 80.8% ( $n=135$ ) had children of their own (Table 1). Most respondents were living together with a partner (71.0%,  $n=127$ ), of whom 58.7% ( $n=105$ ) were married, 2.8% ( $n=5$ ) had a registered partnership and 9.5% ( $n=17$ ) were cohabiting. One of the respondents (0.6%,  $n=1$ ) completed school to primary level, whereas 17.7% ( $n=29$ ) had secondary education and 81.7% ( $n=134$ ) completed tertiary education.

### *Characteristics of the donations*

Almost all donors (94.9%,  $n=156$ ) had donated before 2004. Most (81.1%,  $n=142$ ) donated anonymously, 14.3% ( $n=25$ ) non-anonymously (open-identity to donor-conceived persons from the age of sixteen) and 4.6% ( $n=8$ ) both anonymously and non-anonymously. The majority (90.4%,  $n=161$ ) had informed others about the donations at the time of registration in the KID-DNA Database, while only 9.6% ( $n=17$ ) did not tell anybody about it. There were two donors (1.1%,  $n=2$ ) with family members who had also donated. The estimated period of donations is shown in Table 1. Most of the respondents (42.4%,  $n=70$ ) had donated in the 1980's.

#### *Motivations to become identifiable*

Table 2 shows the categorized and coded responses to the question about the motivations for registration in the Fiom KID-DNA Database. Some respondents gave only one motivation while others gave more. Therefore, the second column presents the percentages of the number of respondents ( $n=179$ ) and the third column the percentages of number of responses ( $n=687$ ). When analysing the data, the distinction between donor-oriented and child-oriented motivations became so visible that it was considered useful to present this in the findings. Most responses (67.2%,  $n=462$ ) were child-oriented: the respondents indicated that donor-conceived persons are entitled to the donor's physical and social data, others wanted to provide their offspring with the opportunity to ask questions, contact or meet them, one donor wanted to give them the opportunity to use his DNA even after his death, another wanted to offer the opportunity to meet same-donor offspring. However, one-third of the responses (32.8%,  $n=225$ ) were donor-oriented: donors were curious whether children were conceived with their sperm, how their offspring are doing, others wanted to have contact or meet them, and one donor was curious about the next generation.

Table 2. Motivations for registration in the Fiom KID-DNA Database.

	responses	% based on the total number of	
		respondents ( <i>n</i> =179)	responses ( <i>n</i> =687)
<i>Child-oriented</i>			
I think that the children conceived with my sperm are entitled to physical and social details	159	88.8	23.1
I think that the children conceived with my sperm are entitled to ask me questions	162	90.5	23.6
I think that the children conceived with my sperm are entitled to meet me	133	74.3	19.4
Other: passing on medical information	2	1.1	0.3
Other: I want to give children the opportunity to contact me	4	2.2	0.6
Other: I want to give children the opportunity to match my DNA even after my death	1	0.6	0.1
Other: I want to give the children the opportunity to meet same-donor offspring	1	0.6	0.1
<b>Total child-oriented</b>	<b>462</b>		<b>67.2</b>
<i>Donor-oriented</i>			
I want to know if there are children conceived with my sperm	56	31.3	8.2
I want to know how the children are doing	65	36.3	9.5
I want to have contact with the children (by letter, email or telephone)	48	26.8	7.0
I want to meet these children	55	30.7	8.0
Other: I am curious about the next generation	1	0.6	0.1
<b>Total donor-oriented</b>	<b>225</b>		<b>32.8</b>

Two donors (1.1%,  $n=2$ ) reported only donor-oriented motivations, 97 donors (54.2%,  $n=97$ ) reported only child-oriented motivations, and 80 donors (44.7%,  $n=80$ ) reported both donor-oriented and child-oriented motivations.

In answer to the question about the reason for donors to abolish their anonymity half of the respondents (50.9%,  $n=90$ ) indicated that their motivation sprang from familiarity with the existence of the Fiom KID-DNA Database. Some donors wanted to be identifiable since their donation (14.7%,  $n=26$ ), while for others (2.3%,  $n=4$ ) this desire grew over the years. Some were influenced by media (15.3%,  $n=26$ ), the birth of their own children (9.0%,  $n=16$ ), or the growing awareness of the importance of contact for donor-conceived persons (8.0%,  $n=14$ ).

#### *Significant others*

Most respondents (76.2%,  $n=131$ ) had a partner who supported their decision to become identifiable at the time of registration in the KID-DNA Database, although 1.7 % ( $n=3$ ) of the respondents had a partner who did not agree to it and a few (5.8%,  $n=10$ ) did not inform their partner.

Almost half of the respondents had children of their own (40.6%,  $n=69$ ) who supported their decision at the time of registration, although 1.8 % ( $n=3$ ) of the respondents had children who did not agree and some (35.3%,  $n=60$ ) did not inform their children.

#### *Desired outcome*

Respondents could indicate how important a match with their donor offspring was on a scale of 1-10 (1=not important, 10=very important). Approximately one-third of the respondents (32.4%,  $n=58$ ) found it very important (score of 8-10), 15.6% ( $n=28$ )

considered it important (score of 7), 10.1% ( $n=18$ ) was neutral (score of 6), and 37.4% ( $n=67$ ) did not consider it important (score of 1-5).

## **Discussion**

This study showed that anonymous donors who decided to become identifiable in the Netherlands have gradually become more aware of the importance of genetic origin to donor-conceived persons. The current public and political debate has informed donors about the struggles of donor-conceived offspring and made them aware of the existence of the national Fiom KID-DNA Database. This is in line with the ideas of Daniels (2007) who argued that donors will be more likely to be influenced and endorse the open-identity policies in societies moving towards openness. After the public appeal from the Dutch Minister of Health, Welfare and Sport, and removal of the registration fee, a significant number of donors (21.5%,  $n=96$ ) registered in the Fiom KID-DNA Database. This demonstrates the effect of openness about the struggles of donor-conceived offspring and how the removal of the financial barriers of a registration fee positively influenced donors' willingness to release their identity. In addition, the awareness of the existence of the database motivated donors to register for their own interest to satisfy their curiosity in their donor-conceived offspring.

These new developments, the media coverage of recent years about sperm donation in the Netherlands and the support of the Minister of Health, Welfare and Sport, may be an explanation for the difference in the number of registered donors in the Fiom KID-DNA Database ( $n=534$ ) compared with the UKDL ( $n=91$ ). Among the 21 UK sperm donors studies by Blyth et al., (2017) their motivations showed many similarities with those of the current study of 179 Dutch sperm donors. Donor-oriented (in donor's own interest) and child-oriented (to help donor-conceived persons)

motivations were evident in both studies. However, in the study of Blyth et al. (2017) 8 donors (38%,  $n=8$ ) indicated that they want to be able to pass information about genetic relatives to their own children or family. This motivation was not found in the current study.

The results of this study only relate to donors who had made themselves known through registration in the Fiom KID-DNA Database and are therefore not representative of the total group of sperm donors in the Netherlands, including those who want to remain anonymous. Furthermore, the numbers of anonymous donors before 2004 are not available due to an incomplete or sometimes even absent registration. Hence it is unknown how representative this population of donors is for the total population of anonymous donors in the Netherlands.

The findings in this study showed that anonymous donors can change their point of view on anonymity. It is likely that that current open-identity donors can change their mind as well and therefore both donors and sperm bank professionals cannot fully anticipate the donor's future view on anonymity. However, a recent study on the open-identity program of the Sperm Bank of California that opened in 1982 (Scheib, Ruby, & Benward, 2017), demonstrated that 18 years after donation, 90.7% ( $n=39$ ) of the donors were still willing to release their identity.

One-third of the cited motivations in this study were donor-oriented: donors were curious whether children were conceived with their sperm, how their offspring were doing, others wanted to have contact or meet them, and one donor was curious about the next generation. Similar findings were found in research into the need for information and guidance for donors. For example, Van Rooij & Mochtar (2017) showed that there were donors who want to know how many children were born after their donations, whether these children grew up healthy and they wanted to be informed about possible

genetic abnormalities found among the children. They believed it was important that, if their offspring wanted to contact them after 16 years, good guidance should be offered. Other research indicated that donors can have concerns about how to deal with large numbers of offspring and how this will affect their families and their lives (Freeman, Jadva & Slutsky, 2016; Wright, 2016).

In conclusion, the findings of this study suggest that anonymous donors can be effectively motivated to release their identity if they are informed, about the existence of genetic databases, such as the Fiom KID-DNA Database, and/or have knowledge about the importance of information for their biological offspring and/or are curious about their offspring. This study showed a considerable increase in donor registrations after the public appeal of the Dutch Minister of Health, Welfare and Sports and the removal of the financial barriers of a registration fee, indicating that openness, media attention and recognition by the government have a positive influence on the willingness of donors to make themselves known.

Internet, social media, donor registers and international genetic databases break the anonymity of donors and affect the privacy of all those involved. Further research is needed to develop guidelines with the aim of addressing the issues surrounding disclosure of identity in a constructive manner, so that the realization of meaningful contact, if desired, is viable. Therefore, it is recommended to focus future research on the psychosocial consequences on donor's family life before and after meetings with donor offspring, and also to pay attention to effective counselling.

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