



Specialist help in case of
unwanted pregnancies and
for questions about ancestry

**10 years of experience with
the search of genetic family**

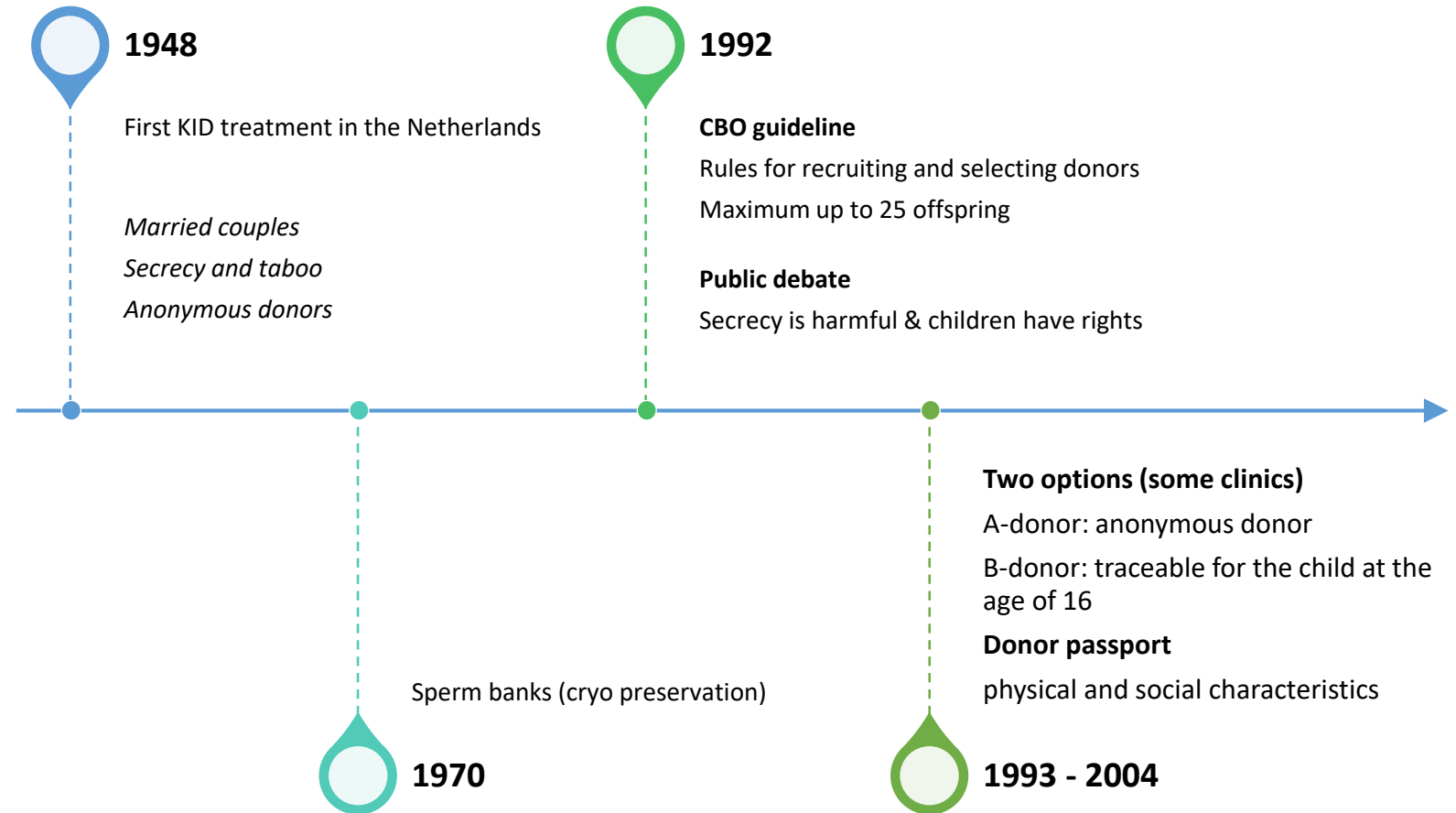
Fiom KID-DNA Database

Dr. Janneke Maas, Fiom (NL), April 16, 2021



Era of anonymous donation

40.000 DCP





2004 Information Donor Insemination Law

(Wdkb: Wet donorgegevens kunstmatige bevruchting)

Persons who were conceived as a result of donor
insemination from 2004 and onwards are entitled to
information about their ancestry

Donor anonymity abolished

2021: First children turn 16



Who is the sperm donor?

2010 Fiom KID-DNA Database

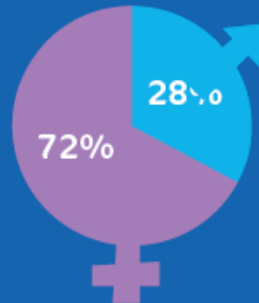


10 years From KID-DNA Database

Who are registering in the database?

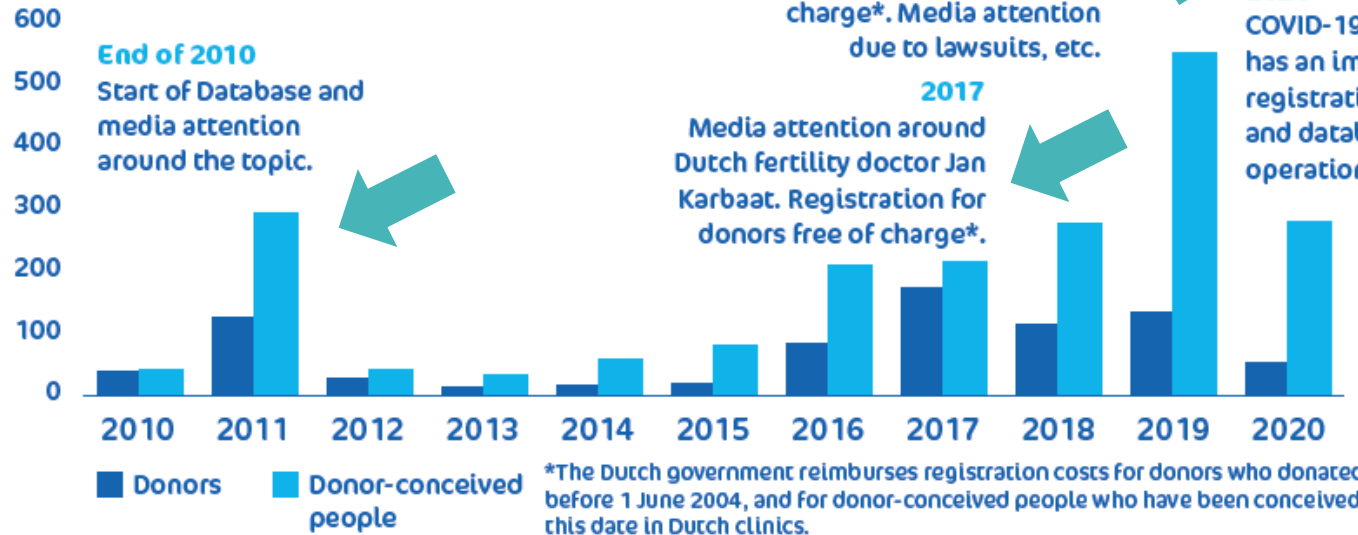


769
donors,
average age
66 years old



1976
donor-conceived
people,
average age
32 years old

Number of registrations



End of 2010
Start of Database and
media attention
around the topic.

2017
Media attention around
Dutch fertility doctor Jan
Karbaat. Registration for
donors free of charge*.

End of 2018
Registration for donor-
conceived children free of
charge*. Media attention
due to lawsuits, etc.

2020
COVID-19
has an impact on
registrations
and database
operation.

*The Dutch government reimburses registration costs for donors who donated sperm before 1 June 2004, and for donor-conceived people who have been conceived before this date in Dutch clinics.



Registration numbers increase due to media attention, political interest, and the removal of financial thresholds.



Donors are motivated due to awareness of the importance of ancestral information for donor-conceived people.



It remains a top priority to reach anonymous donors who have not made themselves known.



Specialist help in case of unwanted pregnancies and for questions about ancestry

More registrations lead to more matches

In the past 5 years, the Database has grown 4 times its original size. The increase of registrations has led to an increase in the number of matches.

2015



12% of donor-conceived people match with a donor



14% of donors match with one or more donor-conceived people

2020

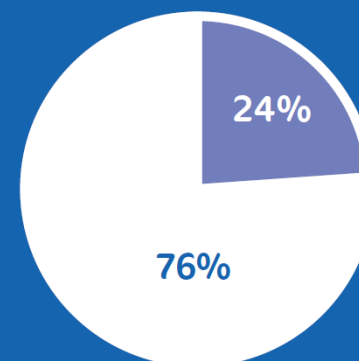


37% of donor-conceived people match with a (virtual) donor



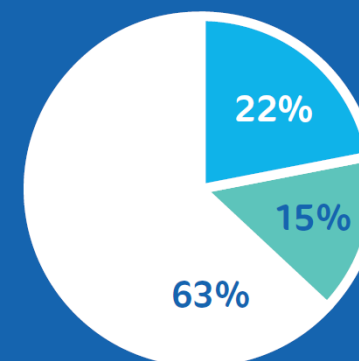
24% of donors match with one or more donor-conceived people

Total number of matches in 10 years



Matches of donors with donor-conceived people (N=769)

- Match with one or more donor-conceived people
- No match yet

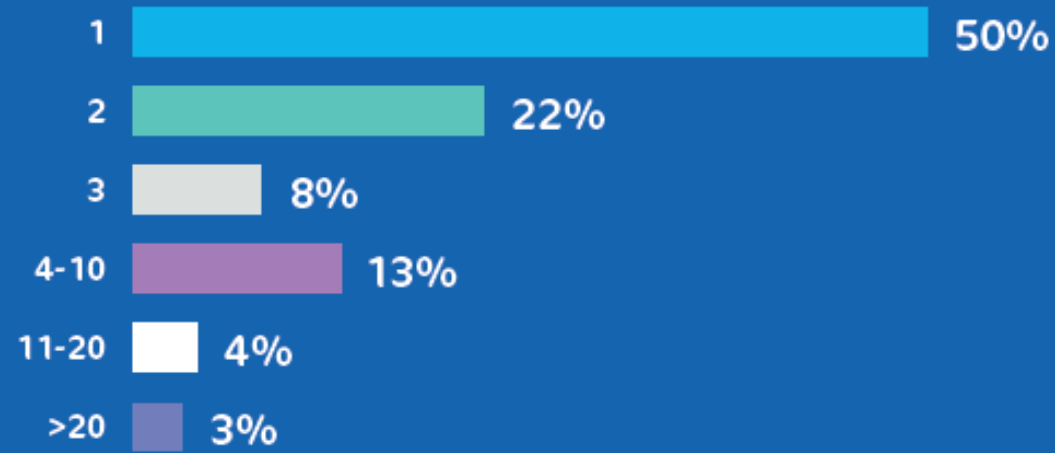


Matches of donor-conceived people with donors (N=1976)

- Match with donor
- Match with virtual donor profile*
- No match yet

*A virtual donor profile is a DNA profile that may be created under specific circumstances without the donor being registered.

Number of matched donor-conceived people per donor (N=182)

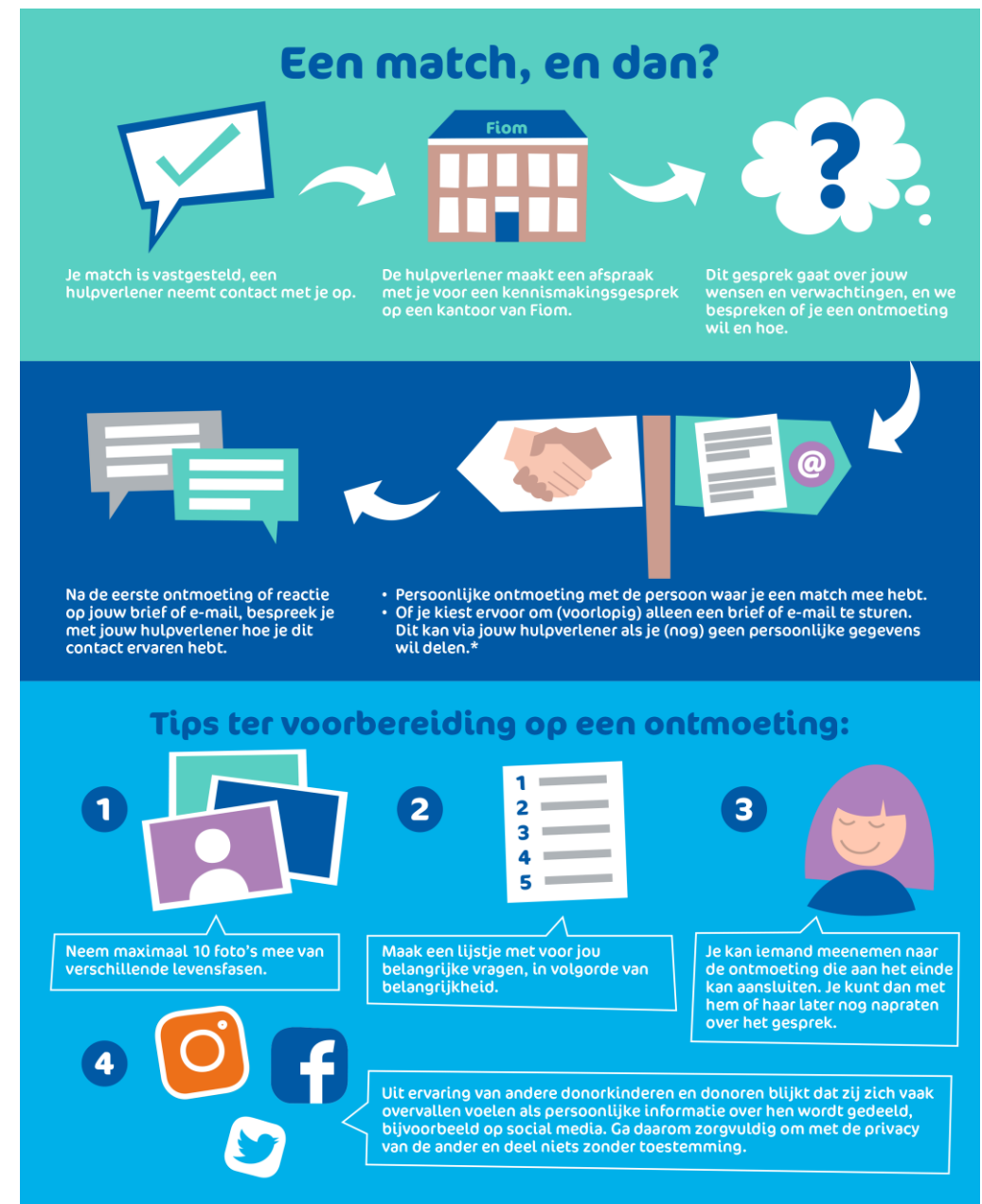


> 800 DCP have a match with one or more same-donor offspring

Amendment Wdkb

Professional support

- Donor conception expertise and experience
- Talk to neutral person
- Preparing for contact/meeting
- Reflect on expectations
- Reflect on feelings
- Sharing concrete examples
- Follow-up calls after contact/meeting
- Advice on the use of social media
- Advice on respecting each other's privacy



Variety



Need of support



Kind of support



Timing of support

Challenges donor

- Age of the donor → older & younger
- Network of donor:
 - Partner
 - Children of the donor within the family
- Deceased donor



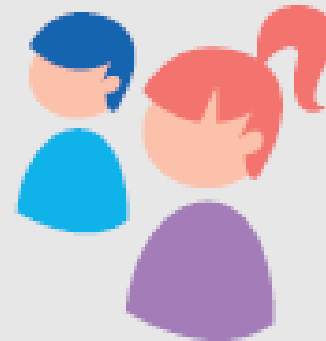
Specialist help in case of
unwanted pregnancies and
for questions about ancestry



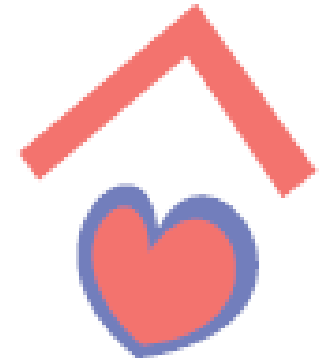
179 male respondents who
donated anonymously in
the past



Average age:
63 years old



Children:
81% raised
children



Marital status:
71% living
together with a
partner

Challenges DCP

- Age of the donor-conceived person
- Network of donor-conceived person
- Siblings within the family with the same (?) donor
- Number same donor-offspring



Challenges: groups of same-donor offspring



“You have never seen them and in the meantime you have so many similarities.”

39

60

“I want to stay in it but investing time is difficult.”

38

“I find it a bit tiring, how many will there be?”

44

26

48

“I think it's sad that the new people are welcomed with less enthusiasm, so I try to do my best.”

Other challenges

- Matches in commercial DNA-databases
 - Unexpected discovery of being DC
 - Donor can be found (no guarantee of anonymity)
- Hereditary diseases
 - Right to know and right not to know
- Inappropriate behavior



Living **DNA**

[GED
match]

 **MyHeritage**

 23andMe

Cross-border challenges

- International sperm banks
 - Who is responsible for sharing information?
 - Same donor offspring in different countries



The founder of the Danish sperm bank that exports to 80 countries in the world explains why Danish men love to donate their sperm

Making little Vikings: The Danish clinic providing the world with sperm



Specialist help in case of
unwanted pregnancies and
for questions about ancestry



Specialist help in case of
unwanted pregnancies and
for questions about ancestry

Conclusion





Specialist help in case of
unwanted pregnancies and
for questions about ancestry

Thanks!

jmaas@fiom.nl





References

- Bolt SH, Postema D, van der Heij A, Maas, AJBM. Anonymous Dutch sperm donors releasing their identity. *Hum Fertil (Camb)* 2019;1-7.
- Crawshaw M. Direct-to-consumer DNA testing: the fallout for individuals and their families unexpectedly learning of their donor conception origins. *Human Fertil* 2018;21:225-8.
- Crawshaw M, Frith L, van den Akker O, Blyth E. Voluntary DNA-based information exchange and contact services following donor conception: an analysis of service users' needs. *New Genet Soc* 2016;35:372-92.
- Daniels KR, Kramer W, Perez-y-Perez MV. Semen donors who are open to contact with their offspring: issues and implications for them and their families. *Reprod Biomed Online* 2012;25:670-7.
- Janssens, P.M.W., Simons, A.H.M., Van Kooij, R.J., Blokzijl, E., & Dunselman, G.A.J. (2006). A new Dutch Law regulating provision of identifying information of donors to offspring: background, content and impact. *Human Reproduction*, 21, 852–856.
- Regalado A. More than 26 million people have taken an at-home ancestry test. *MIT Technology Review*. Available at: <https://www.technologyreview.com/2019/02/11/103446/more-than-26-million-people-have-taken-an-at-home-ancestry-test/>