

Donor anonymity and right of access to personal origins

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Fundamental premise in all donor conception regulations

- The recipient parent(s) will be the child's real parent(s) from the beginning
- The donor has no form of parental responsibility and may not claim any family rights:
 - as long as regulated treatment in licensed clinics are used
 - informal donors may claim for asserting parentage (UK , Belgium, Quebec, BC)
- The couple receiving the donation become the legal parents of the child according to the general rules governing legal parentage
- With the exception of special cases, claiming or challenging the legal parentage of the child born as a result is forbidden

The previous prominent trend : anonymous donor

- Until recently, most gamete donation through clinics was anonymous
- Strict application (e.g., in France): cross-donation programme for those who bring their own donor (donors are exchanged between recipient couples)
- Countries where anonymity is still mandated by law
France, Belgium, Spain, Portugal, Greece, Denmark, Bulgaria, Czech Republic

The anonymity doctrine

- The French model
 - originating in deontological policies designed by the National Federation of Centers for the Study and Storage of Human Egg and Sperm Cells (CECOS).
 - imported from blood-bank policy
 - enshrined in the 1994 bioethics law
 - applied to the donation of all parts and products of the human body
 - followed throughout Europe in the early years
- Reasons in favour of anonymity
 - removes any moral ambiguity from sperm donation likened to adultery
 - Corollary of the principle of gratuity and non commodification
 - Screen preserving the parent's privacy and making easier for the sterile parent to assume his/her parental role
 - Makes it easier to attract sperm donors

Exemptions

- Known donation practice

- Belgium: a non-anonymous gamete donation is possible in the case of an agreement between the donor and the recipient(s).
- Denmark: donors can choose whether to donate anonymously or not .

- Medical Exemptions

- France, Belgium : medical information can be shared with a GP at the donor-conceived person's request.
- Spain: identifying information could be disclosed where there is a serious illness .

Shift towards increasing access to donor information

- New trend based on concern for the human rights of donor-conceived offspring.
- A number of European countries have provided statutory access to donor-identifying information for children born through gamete donation on reaching maturity
 - Sweden: the first country in the world to lift the donor-anonymity rule in 1985
 - Netherlands: donor-conceived people have a statutory right to request identifying information about their donor from the age of 16
 - Norway, Iceland, Switzerland, Austria, Germany
 - the UK : iconic regulation in 2004 (Disclosure of Donor information 2004 + Opening the Register HFEA policy + 2008 HFEAct) - see hereafter

=> contrasting approach

Access to non-identifying information (UK and Holland)

- **Prospective parents** (in the UK and Holland) could request non-identifying information about donors.
- **Donors** may receive non-identifying information about the number, sex and date of birth of their offspring
- **Children**
 - upon reaching sixteen
 - may contact the national donor registry to determine whether they were conceived with donor gametes .
 - With a donation made after April 2005 (UK), can receive information about the donor.
 - with donations made after April 2005 (UK), may discover if they are genetically related through gamete donation to an intended spouse or intimate partner .
 - // Holland from the age of 12

Access to donor identity (UK and Holland)

- Children, once they reach the age of 18 (Holland: 16),
 - Can receive identifying information about the donor
 - With mutual consent, may also receive identifying information about donor-conceived genetic siblings .
- Donors
 - prior to April 2005 may elect to remove their anonymity .
 - must be contacted to let them know that identifying information has been requested and must be offered counselling

The right to access to personal origins is heavily supported by the ECtHR

- Increasing weight to the child's right to know his/her genetic origins under the principle of personal autonomy contained in the right to respect for private and family life (art. 8)
- The case of *Jäggi vs Switzerland*, July 13, 2006 and case of *Pacaud vs France*, June 16, 2011 are particularly noteworthy.
- No case has considered the specific question of access by donor-conceived people to information about their donor.
- A claim for access to donor identity has been submitted by French plaintiffs (members of a support group)

Expectations about the ECtHR position

- When no common position , ECtHR allows the CS a wide margin of appreciation
- But ECtHR is usually sensitive to shifts in balance and to the emergence of any new consensus
- The ECtHR is unlikely to recognize an absolute right to know the identity of the donor
- Probably would recommend a compromise modeled on the one that emerged from the case of *Odièvre vs France*, February 13, 2003
 - fair balance between the preservation of donor anonymity and the child's right to know his/her biological parents' identity
 - It would imply the existence of a specific procedure enabling access to sperm-donor identity

Any right to access is subject to the child being informed of the donation conception

- Pivotal point : the disclosure of donor conception to the children
- Studies report
 - Parents generally intend to share information about the use of a donor with their offspring
 - but express uncertainty about how and when to tell the child about his/her conception
 - Information-sharing is a long and uneasy process
- Is there a right to know for donor-conceived people ? Is there a duty upon the State to ensure that all donor-conceived people know about their origins ?
- No European legislation has obliged any parents to disclosure and information- sharing with their children

Victoria (Australia)'s unique regulation

- Victoria first established a mandatory registry of donors and recipients in 1988.
- In addition, since 2010, when donor-conceived individuals apply for birth certificates, they must be provided an addendum to their birth certificate that states that more information is available about their birth
- This means that all individuals born after 2010, once they reach the age of eighteen, who happen to request their birth certificate, could discover that they were donor-conceived even if their parents have not chosen to reveal that information.

Are anonymity as well as disclosure obsolete ?

- A donor conceived person can order an inexpensive DTC-DNA test and learn that his/her does not match his/her legal parenthood
=> Increasing likelihood of unplanned disclosure
- A French donor conceived person managed to find his biological father thanks to a genetic test and via Facebook (bombshell announcement in January 2018)
=> the principle of anonymity is undermined
- Potential parents and donors have to be warned that there can be no absolute guarantee of anonymity and privacy even if these principle are enshrined in law

What conclusion ?

- To put a reference to donor conception on the birth certificate to ensure that this person eventually knows that he/she is donor conceived would be stigmatising and would amount to a breach of the right to respect for private life
- Disclosure cannot be a compulsory duty upon parents, but only a favoured option in reference to human rights and in an increasing context of openness and transparency
- Instead of driving donor-conceived people to ordering wild DTC DNA test, wouldn't it be better- in the States where it is still legal- to ban anonymity and to frame a process where States will have a stewardship role (ensuring an appropriate intermediary and counselling service) ?