



K N O W I N G H I S

O R I G I N S

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**D O N O R
C O N C E P T I O N**



O R I G  **N E S**

www.associationorigines.com

AUDREY ET ARTHUR KERMALVEZEN



Who are we ?

- **Arthur Kermalevezen** : donor-conceived person, he always knew. It wasn't a secret. In 2006, he began to testify publicly of his need to know who the donor is.
- In 2017, through a DNA-test bought on the web, he found his donor in 11 hours. Gerard the donor lives 150 km from us.
- **Audrey Kermalevezen** : she chose to specialize as lawyer in bioethical law and she discovered 6 years later (in 2009) that she had been conceived by a donor (she was 29 years old).
- She asked the french hospital :
 - if she has the same donor as her brother and as her fiancé (Arthur)
 - if her donor is dead.
 - and if he's still alive that this question could be asked to him :
do you want to stay anonymous or would you like to give some piece of information such as a photo of you or your medical history?
- Everything was denied. She lost each trial. She filed a request to ECHR in 2016 and her request is closed to being judged (probably in the second semester of 2023).
- Arthur et Audrey founded **ORIGINES** which is an association of donor conceived people, donors and parents that helps everyone searching for his or her origins and tries to convince the politicians and the public of the need to change the law

● The new french bioethical law : What changes ? For who ?

Loi 2021-1017 du 2 août 2021
Décret n° 2022-1187 du 25 août 2022
Avis Cnil n° 2022-042 du 7 avril 2022
Arrêtés du 29 août 2022

- **For donors** : effective changes from 1 september 2022
- **For parents** :
 - Assisted reproduction by donor was opened to women in same-sex couples and single women
 - A legal recommandation : each parent is now incited to tell the truth to his or her child about donor conception
- **For donor conceived people** : for the moment, very few changes

- Since 1st september 2022

For gametes (sperm, eggs) ou embryos donation, you have to :

1/ leave your **identity** : last name, first name, gender, date and place of birth

2/ fill out a legal form which contains **non-identifying data**

All these information (1 + 2) will be **transmitted automatically to the child** from 18 year old if he or she asks for it.




Problem :
all the gametes and embryos donated since 1st
september 2022 are **unused**

French doctors should **primarily** use gametes and embryos donated before 1st september 2022.

For every child conceived by donor today, there's **no right** no guarantee to access to information, even non-identifying data, without donor consent.

These children will only find out at the last moment (when they will be 18 years old) if yes or no, their donor agrees to give information.

3 situations are possible



First situation : the donor consents to give his or her identity


No problem, except 3 :

- 18 year old is late to have access to that kind of fundamental information.

For example in Quebec they are preparing a law and donor conceived people could have access to donor identity since their birth (no minimum age) with parents consent and at 14 years old without parents consent.

- Children will never know donor's medical history. For this, the child has to contact and ask the donor.
- In all cases, donor-conceived child will never have any information about his siblings (people conceived by the same donor). He can have that kind of information by making a DNA test but it's legally forbidden in France).

(These 3 problems will exist also for children that would be conceived by eggs and gametes donated since 1st September 2022)



Second situation : the donor refuses to give his identity and accepts to give only non-identifying data

The donor should fill a legal form which is not satisfactory.

For example it contains absolutely **no medical information** about the donor, except minimum information that is completely useless :

-What was your general physical condition when you donated your gametes (for example 42 ou 18 years before) ? Very good, good, middle, bad or very bad. The donor can't explain anything. Just answers bad or good, that's all !

- Can you rate (from 0 to 10) your state of mental health when you donated your gametes ? The donor can't explain why he put a 10 or a 2 for example.

- How often do you practice physical activity or sport when you donated your gametes? Without being able to tell for example what kind of sport is being undertaken.



Legal form contains nothing about the donor's personality or anything that could help to imagine or represent him.

There is a **physical description** but for example skin color : you have to choose between very light skin or very pale skin or dark skin or very dark skin (instead of having Asiatic type, African type, European or Caucasian type... for example).

It's the same for donor's **motivations** :

The donor can write a short text to express his motivation for being a donor but if he puts anything that could be identifying, the doctor can tell him to delete the sentences.

And more, the donor can avoid writing a text and can just check boxes like :

☐ I'm a donor because I want to help someone to become parent.

☐ I'm a sperm donor because I'm a blood donor...



Third situation :

- the donor is **not localizable**
- the donor **refuses** (to give any information even non-identifying)
- the donor is **dead**

Children can't have access to any information :
neither donor's **identity**, nor **non-identifying data** like
the reason of his death for example.

● Can France be condemned by ECtHR ?

I think so

1/ The new law (Bioethical law 2 august 2021) doesn't change anything for me.

French administration sent me a letter in March 2023 to tell me that my donor is dead (**14 years after my first application** !) and they added that they can't give me any information because the donor didn't consent before dying. So I can't know (without making a illegal DNA-test) :

- if my brother and I have been conceived by the same donor
- if my husband (Arthur) and I have been conceived by the same donor
- if I have siblings in nature and how many and who they are
- the medical history of my donor while it's still in his file in the french hospital...



Can France can be condemned by ECtHR ?

2/ The french legislation is not **a fair balance between the different parties involved.**

Compared secret childbirth (accouchement sous X) :

- the children (born under X) can have access to **non-identifying data** about his or her biological parents and biological siblings without biological parent's consent in his adoption file.

Donor conceived people : no adoption file and no file at all.

- if the **biological mother dies** before the administration ask her if she wants to stay anonymous or not, **her identity is transmitted to the child.**

● Can France be condemned by ECtHR ?

3/ For donors before 1st september 2022, the french legislator chose to limit the access to donor's identity only if donor consent when he will be asked for :

✗ But this condition wasn't justified concerning donors before first bioethical law of 29 july 1994 : no legal anonymity

✗ This condition wasn't necessary about others donors (between 29 july 1994 and 31 august 2022) because the french principle of anonymity concerns only the donor and the recipient. It doesn't concern the child who has been completely forgotten.

● What is the dream bioethics law ?

- Legalization of DNA testing (ancestry ones)
- Create an anonymous exchange platform between donors and donor conceived people (that permit discovering each other step by step, updates to medical data in real time...)
- Contacting all the past donors to ask them if they accept the new conditions (to accelerate the creation of the new gametes stock)

● What is the dream bioethics law ?

- Transmission to parents non identifying data about donor (for example medical history) from the birth of their child.
- Transmission to donors the number and the gender of children born by their donation.
- Transmission to donor conceived people : donor's medical history and informations about siblings.