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TO KNOW OR NOT TO KNOW: THE RIGHT TO INFORMATION ABOUT DONOR IDENTITY UNDER UKRAINIAN LEGISLATION[1]

ЗНАТИ ЧИ НЕ ЗНАТИ: ПРАВО НА ІНФОРМАЦІЮ ПРО ДОНОРА СТАТЕВИХ КЛІТИН У ЗАКОНОДАВСТВІ УКРАЇНИ

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This article is dedicated to the problem of right to access to information about donor identity for donor-conceived people. The author reaffirms her previous conclusions that the current international legal framework does not directly regulate and protect the right to information about donor identity. The article goes on to investigate the experience of those countries where the right to information on one`s genetic origin is foreseen by the legislation: Sweden, the first to introduce such a right, the United Kingdom and France. It is interesting to see the reasoning behind the requests to disclose information about the donor. As the research in Sweden shows, most often, donor-conceived people were guided by an interest in seeing whether they had any physical resemblance with their genetic parents or any similarity in their non-physical characteristics. Moreover, the applicants also showed an interest in information on the donor`s heritage, medical background and also in contacting the family of their donor. The study of statistics in the United Kingdom and in Sweden proves that donor-conceived people who are eligible to apply do so.

The purpose of this article is to analyze the recent applications filed before the ECtHR concerning information on donor identity (Gauvin-Fournis v. France and Silliau v. France) and to predict what possible implications they might have for Ukraine. Another of the article's aims is to analyze current legislative initiatives regarding the right to access donor identity and check whether they meet European standards or not.

The author comes to the conclusion that current Ukrainian legislation fails to regulate the possibility of access to information about donor identity and formulates solutions to bring Ukrainian legislation in line with European standards. The absence of the right to information on one`s genetic origin can lead to applications before the ECtHR, as we now observe in the pending applications of Gauvin-Fournis v. France and Silliau v. France; if the ECtHR decides in favour of the applicants, we may predict the occurrence of similar cases in Ukraine.

Key words: European Court of Human Rights, reproductive rights, right to information on donor identity, right to information about genetic origin.

Стаття присвячена праву осіб, зачатих за допомогою допоміжних репродуктивних технологій, на доступ до інформації про їх донора. Авторка підтверджує свої попередні висновки про те, що міжнародні правові акти не містять норм стосовно реалізації згаданого права, його охорони та захисту. У статті досліджено досвід тих країн, якими право на доступ до інформації про генетичне походження закріплено на законодавчому рівні: Швеції, де таке право було врегульовано раніше, ніж в інших країнах, Великобританії і Франції. Цікаво зрозуміти причини, якими особи, зачаті за допомогою допоміжних репродуктивних технологій, обґрунтовують необхідність розкриття інформації про донора статевих клітин. Як свідчить дослідження в Швеції, найчастіше заявників цікавить, чи схожі вони зовнішньо на генетичних батьків, або чи мають вони якісь інші спільні риси. Також заявників цікавив спадок донора, медична інформація й можливість контакту із сім`єю донора. Аналіз статистики у Великобританії та Швеції свідчить про те, що особи, зачаті за допомогою допоміжних репродуктивних технологій, які відповідають законодавчим вимогам (наприклад, досягнення певного віку) – здійснюють це право й подають заяву на розкриття інформації про їх донора.

Авторкою проаналізовано також зміст заяв до Європейського суду з прав людини щодо розкриття інформації про донора статевих клітин (Гован Фурні проти Франції та Сілло проти Франції) і подано висновок про їх можливий вплив на законодавство України. Метою статті є й дослідження останніх українських законодавчих ініціатив щодо інформації про донора статевих клітин та формулювання висновку про те, чи відповідають вони європейським стандартам.

Авторка дійшла висновку, що чинним законодавством України не передбачено можливості отримання інформації про донора статевих клітин і подає пропозиції щодо приведення вітчизняного законодавства у відповідність з європейськими правилами. Відсутність законодавчо передбаченої правомочності на отримання інформації про своє генетичне походження спонукає до подачі заяв до Європейського суду з прав людини, на кшталт заяв у справах Гован Фурні проти Франції та Сілло проти Франції; якщо Європейський суд з прав людини прийме рішення в цих справах на користь заявників, то існує висока ймовірність подання відповідних заяв і проти України.

Ключові слова: Європейський суд з прав людини, репродуктивні права, право на інформацію про донора статевих клітин, право на інформацію про генетичне походження.

Donor-conceived people in Ukraine do not have the right to access information about their donors because egg, sperm and embryo donation in Ukraine are anonymous. As a result, donor-conceived people cannot get access to information about their genetic origin. This experience may be traumatizing. To get an idea of the potentially detrimental effects of having no contact with one's biological mother, one can watch an Australian film called "Lion". The film tells the story of a 5-year-old boy who was lost in India and then adopted by an Australian couple; when the boy gets older, he spends a lot of time trying to find the place where he used to live in India on Google Maps. The film brilliantly depicts all the suffering experienced by a person who is unable to find out about, or has lost the information about, his genetic origin. Therefore, studying the possibility of introducing such a right into Ukrainian legislation is very desirable.

The right to information about one`s genetic origin has been the subject of research by many European authors, namely C. Lampic, J. Millbank, S. Allan, P. Nordqvist, S. Isaksson etc., whereas in Ukraine only several scholars have researched the issue – K. Moskalenko and K. Solodovnikova. It is interesting to look at the recent developments in the European Court of Human Rights (ECtHR) regarding the right to access information about genetic donors and study their potential influence on Ukrainian legislation. The purpose of this article is to analyze the recent applications concerning information on donor identity filed before the ECtHR and anticipate what possible implications they might have for Ukraine. Another aim of the author is to analyze current legislative initiatives

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regarding the right to access donor identity and check whether they meet European standards or not.

In previous publications, the present author came to the conclusion that the current international legal framework does not directly regulate and protect the right to information about donor identity. In particular, Art. 8 of the European Convention on Human Rights (hereinafter ECHR) lays down the right to respect for private and family life, and there have been a number of cases heard by the ECtHR where the right to access information on biological origin or about early childhood was protected. These are the cases of Gaskin v. United Kingdom, Jäggi v. Switzerland, and Godelli v. Italy [1, p. 27–28]. Modern scholars also theorize about the possibility of applying Art. 14 of the ECHR – prohibition of discrimination – because people who were conceived naturally get access to all their genetic information, while those who were conceived by donor eggs and/or sperm lack such access. For example, in British legal doctrine, adopted children can access information about their biological parents, and scholars consider that people conceived by donor should also be granted such access, otherwise it is discrimination [2, p. 88].

The right of donor-conceived children to access information about their donor is foreseen in different *European jurisdictions*. For example, *Sweden* was the first country to enact this right in 1985. Following Section 5 of the Genetic Integrity Act, a person conceived through insemination with sperm from a man to whom the woman is not married or with whom the woman does not cohabit has the right to access the data on the donor recorded in the hospital's special journal, if he or she has reached sufficient maturity. If a person has reason to assume that he or she was conceived through such insemination, the social welfare committee is obliged, on request, to help this person find out if there are any data recorded in a special journal [3]. We can already trace the number of individuals who requested the information about their donor and the reasoning behind such applications. As a study by a group of scholars from Sweden shows, from a total of approximately 900 donor-conceived people who had reached the age of majority at the time of the survey, a total of 60 (7%) requested information about the donor. Most often, donor-conceived people were guided by an interest in seeing whether they had any physical resemblance with their genetic parents or any similarity in their non-physical characteristics. Moreover, the applicants also showed an interest in information on the donor`s heritage, medical background and also in contacting the family of their donor [4].

In the *United Kingdom*, donor-conceived children also have access to information about their donors. The scope of information depends upon the date when the person was conceived: no information is held by the Human Fertilisation and Embryology Authority (the state fertility regulator) on people conceived before August 1, 1991; people conceived between August 1, 1991 and March 31, 2005 can get non-identifying information about their donor[2]; while people conceived after March 31, 2005, can get identifying information[3] [5]. The Human Fertilisation and Embryology Authority states that around 800 donor-conceived people were aged over 18 by the end of 2022, and of these eligible people 28 (3,5%) have already applied for the identifying information about their donor and received it [6].

Some European countries have opted for a legal prohibition on persons born from donated sperm or eggs accessing the identity of the donor. This was the case in *France* until recent legislative changes, and it comes as no surprise that the ECtHR is currently processing 2 applications against France on this matter – Gauvin-Fournis v. France and Silliau v. France. In the first application, Gauvin-Fournis v. France, Mrs. Audrey Gauvin-Fournis was born as a result of assisted human reproduction, using donor`s sperm. She wanted to obtain information about the donor`s identity and non-identifying information, such as age, professional status, physical description, reasons for donation, the number of persons conceived from his gametes and medical data relating to his history. She also wanted to know if her brother was born using the same sperm donor or not. The applicant received refusal both in administrative procedure and in the court. She claims that France has violated her right to respect for private and family life, protected by Art. 8 of the ECHR, by depriving her of access to information about her origins and her parent. She also claims that she is discriminated against in relation to other people in the enjoyment of her private life, because of the impossibility of access to her family medical history. She considers that by not being able to answer doctors' questions about her family's illnesses, she and her children are potentially losing the chance of recovery, diagnosis or preventive care [7]. The application of Silliau v. France is very similar, as the applicant, Mr. Clément Silliau, was also born with the use of donated sperm and wanted to know the identity of the donor, to have access to medical information about him and to other non-identifying information, such as his motivations, his family situation and his physical characteristics. He also claims the violation of the same Articles 8 and 14 of ECHR [8].

It is interesting to review the provisions of French legislation (as of the time of consideration of the cases) that allowed only the doctors to access the information about the donor or recipient. Following Art. 16-8 of the Civil Code, no information enabling the identification of both the person who had donated an element or product of his body and the person who had received it may have been disclosed. The donor could not have known the identity of the recipient nor the recipient that of the donor. In the event of therapeutic necessity, only the physicians of the donor and the recipient may have had access to the information allowing the identification of the latter [7]. The Public Health Code in Art. R. 1244-5 laid down the contents of the donor`s file, which was kept by the medical institutions: the personal and family medical history necessary for the implementation of medically assisted procreation with a third party donor; the results of the health screening tests; the number of children born from the donation; in the case of a sperm donation – the date of the donations, the number of straws kept, the date of availability and the number of straws made available; the written consent of the donor and, if part of a couple, that of the other member of the couple. This file was kept for a minimum period of forty years in anonymous form, and stored under conditions that guarantee confidentiality [7]. It meant that only doctors could have access to the information on the donor in the event of medical necessity. In September 2022 France lifted donor anonymity and allowed access for donor-conceived children who had reached the age of majority to donor identity (surname, first name, date of birth) and non-identifying data about them (age and general physical condition at the time of donation, family and professional situation, physical characteristics, motivations for donation) [9]. This new law does not have retroactive effect and can not be applied in the present ECtHR cases, as the cases' facts date back to 2010. However, donors who donated before September 1, 2022, can lift their anonymity and have their information disclosed to the recipients. It is very interesting to see how ECtHR will decide these cases, Gauvin-Fournis

[2] Including the information on donor's physical description (height, weight, eye and hair colour), the year and country of donor`s birth, ethnicity, whether donors had any children at the time of donation, and any additional information the donor chose to supply such as occupation, religion, interests and a brief self- description. The donors also might opt for disclosing their identifying information. Donor-conceived people who have reached 18 years old may obtain such information.

[3] At 16, the following information may be revealed to donor-conceived: donor's physical description (height, weight, eye and hair colour) if provided, the year and country of donor`s birth, ethnicity, whether donor had any children, how many and their gender, donor`s marital status, medical history, a goodwill message to any potential children (if provided). After reaching the age of 18, identifying information about the donor can be revealed, including donor's name, date of birth and last known address.

v. France and Silliau v. France, because these decisions may directly influence Ukrainian legislation. In particular, failing to provide the applicants even with non-identifying information about the donor and entitling only the doctors to access such information might constitute a violation of the applicants` right to respect for private and family life.

In Ukraine, the current legal framework does not provide for the right of donor-conceived persons to receive information on donor identity. In particular, Art. 290 of the Civil Code of Ukraine foresees that the donor`s identity should not be known to the recipient and vice versa. The only exception to the rule might be in the case of family or marriage ties between the donor and recipient [10]. Following Art. 48 of the Law of Ukraine "Foundations of the Legislation of Ukraine on Healthcare", artificial insemination, conducted with the usage of donated material, can occur only under the condition of donor anonymity. Waiving donor anonymity can take place under those conditions established by current Ukrainian legislation [11]. Up to this time, there is no specific rule on waiving donor anonymity. The Order of the Ministry of Healthcare of Ukraine "On the Order of Application of Reproductive Technologies in Ukraine" regulates donation of gametes and embryos. A number of its provisions provide for donor anonymity, such as the patient application form to use assisted reproductive technologies with the use of gametes/ embryos, which includes a prohibition on the recipients trying to find out the donor`s identity if the donation was anonymous [12].

Some "potential precursors" to the right to information about donor identity may be found in Para 5 Art. 19 of the Draft Law of Ukraine "On Assisted Reproductive Technologies", pursuant to which donors may give consent to the health facility to disclose their personal data when the interests of the future child so require, e.g. for the treatment of hereditary diseases [13]. Art. 20 of the Draft Law of Ukraine "On Application of Assisted Reproductive Technologies" allows for non-anonymous donation of gametes or embryos when the donors are relatives of recipients or the donors and recipients signed a joint application form [14]. Although this article does not foresee the rights of donor-conceived people to access the information about their donor, it at least provides for exceptions to the principle of anonymity. Para 2 of Art. 14 of another Draft Law of Ukraine "On Application of Assisted Reproductive Technologies and Surrogacy Motherhood" allows for the donor to opt for the waiving of anonymity. Upon the donor`s written consent, his or her data can be disclosed to the recipients or to the health facility when the donor is a recipient's relative, when they have mutual consent with the recipients, or when such disclosure is necessary to treat the future child`s hereditary disease [15].

In the opinion of the author, it is not enough to foresee the disclosure of donor identity only when the child has a hereditary disease. The balance of rights between donor-conceived children and donors can be achieved only if legislators waive donor anonymity in the future and allow donor-conceived children to access information about their genetic origin. Donors who provided their genetic material on the basis of anonymity should have the option to waive such anonymity. If they so decide, their identifying information should be provided to donor-conceived children. Such an approach will meet European standards, proved to establish a fair balance between the rights and interests of donor-conceived people and their donors in many European countries, including the United Kingdom and Sweden.

This research allows one to conclude that the right of donor-conceived people to access the information on their donor`s identity is not foreseen in Ukraine. The recent legislative initiatives that took place at the end of 2021 and the beginning of 2022 do not adequately address this failing. The absence of the right to information on one`s genetic origin can lead to applications before the ECtHR, as we now observe with the pending applications in the cases of Gauvin-Fournis v. France and Silliau v. France, and if the ECtHR decides in favour of the applicants, we may predict the occurrence of similar cases in Ukraine, which has not implemented the mechanism to access information on donor identity.

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