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# THE RIGHT TO KNOW ONE’S GENETIC ORIGIN

Master thesis

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# LIST OF ABBREVIATIONS

**EU** – European Union

**ART** – assisted reproductive technologies

**IVF** – in-vitro fertilization

**ECHR** - European Court of Human Rights

**CRC** - Convention of Children Rights

**UK** – United Kingdom

**HFEA** - Human Fertilization and Embryology Authority in United Kingdom

# INTRODUCTION

How often do we think of the fact that many children may never have the opportunity to know their genetic origins? This issue may arise when surrogate mother provides genetic material, sperm donors take part in the assisted reproductive technologies, in case of foster and adoptive families and other situations with misattributed paternity.

Editors of Encyclopedia Britannica define parents as "individuals who have begotten offspring, or one who occupies the role of mother or father".[1] At the same time in various information sources we can find different wordings indicating parents: 'birth parents', 'biological parents', 'gestational parents', 'natural parents', 'social parents', 'legal parents', 'intended parents'. Complicating matters further the term 'biological parent' may have a more complex meaning. For example, in case of egg donations, the biological parent could be either the genetic parent or the birth mother.[2] For the purpose of this research, we will distinguish two categories of parenthood: parents who have genetic relation to the child and parents who are legally recognized as such by the State. Later on, we will operate with all mentioned above wordings. Generally, the division between 2 terms: a 'biological parent' and 'social parent' are made basing on the fact that "the former is 'producing' the child and later acting as a parent in a legal and social sense". In case of fathers, such definitions are also applied: a 'genitor' - a biological father, and a 'pater' - a social one.[3]

When the identities of social and biological parents are not the same, certain concerns appear, particularly: should the person be informed about genetic/birth/biological parents, in what way should they be informed about it, how to avoid psychological harm for the child or even adult person, how to keep the balance between the interests of all involved parties and many other relevant questions.

While considering these issues, the right to know one's genetic origin became a subject of world-wide discussions and brought big attention of the international community.

At the global level, this right is also commonly known as 'the right to know' and is considered as an integral part of such basic human rights as the right to private and family life.[4] It protects each individual's interest to identify where he or she came from. The right to know one's identity has also

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[1] "Parent", Encyclopedia Britannica, accessed 18 January 2020, https://www.britannica.com/topic/parent-kinship.

[2] "Implementation Handbook on the Convention on the Rights of the Child", UNICEF, accessed 25 January 2020, https://www.unicef.org/publications/index_43110.html.

[3] "Parent", Encyclopedia Britannica, Accessed 18 January 2020, https://www.britannica.com/topic/parent-kinship.

[4] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family*, 21(2), (2007):137, https://doi.org/10.1093/lawfam/ebm003.

been guaranteed in the Convention on the Rights of the Child, the Convention on the Protection of Children and Cooperation in respect of Inter-country Adoption, the recent case law of the European Court of Human Right and other relative documents[5] which we will address to while discussing the right to know one's genetic origins.

**Problem of research.** Despite a big moral dilemma of the problem with disclosing biological parents' identity, this is the issue of great legal debates, which arose around the right to know one's genetic origin. Reforming legislation in this sphere has been on the agenda in many countries for the last decades because of the huge progress in medical sciences dealing with reproductive technologies which had created many new possibilities for the donation of genetic material (IVF, ECO, and so forth). The situation becomes even more complicated due to the fact that in many countries there is a long-standing tradition of donor anonymity, which creates a barrier for the children seeking for their origins.

The general issues can be stated as the necessity of disclosure such information taking into account different conditions, one of which is the best interest of the child. How the 'ideal' concept of the provision regarding the right to information about donor identity should be stipulated? Is it possible to formulate such a one at all? Are donor-conceived individuals granted the same right to search for biological parents as adoptees? How the process of seeking for origins should be regulated?

Another problematic issues arise while balancing the rights of children and parents. Parent's attitude towards the disclosure information of origin plays a significant role in this regard. Even if the State provides a legal mechanism for searching for genetic relations, the person can use such an opportunity only if he or she is aware of the mere fact that another person was involved in her birth. In this case, disclosure is fully dependent on the willingness of social parents and therefore they can easily deprive the child of the potential possibility to know the truth.[6]

Taking into account this situation, the research question is: **Should the right to know one's genetic origin be unconditionally stipulated and regulated by law?**

**Relevance of the final thesis.** Taking into account the rapid development of reproductive technologies, its growing popularity and interest of adopted individuals as well, it is necessary to understand the ways for establishing the right to know genetic origin on the level of State's regulation

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[5] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family*, 21(2), (2007):137, https://doi.org/10.1093/lawfam/ebm003.

[6] Guido Pennings, "The 'double track' policy for donor anonymity", *Human Reproduction* 12,12 (1997):2840.

and balance it towards the secrecy of donorship, which is recognized by the State in many jurisdictions. Additionally, it is important to understand the guarantees for the respect of this right.

**Scientific novelty and overview of the research** on the selected topic of Master Thesis is that there is a need for the development of recommendations on possible solutions on improving access to the information about genetic origin and prevention of the misbalances between the rights of donors, social parent, and offsprings. The present research problem has been investigated by a number of researchers, particularly ones working on regulation of bioethical dilemmas in law and medical science, such as Vardit Ravitsky[7], Samantha Besson[8], Elodie Decorte[9], Brigitte Clark[10], Jane Stoll[11], Janne Rothmar Herrmann[12] and others.

**Practical significance** of the paper is connected with the contribution of the author's research into understanding the concepts, personal scope and main problems of the right to know one's genetic origin within Europe. The results of the study will be useful to understand the shortages of legislation on family law, human rights law, regulations in the sphere of ART, and given recommendations will be helpful to make changes, including legislative ones, in order to find the possible options for legislative solutions.

**The aim of the study** is to study the existing legislative provisions enabling individuals to obtain information concerning their genetic origins, identify limitations of donor anonymity and, taking it as a basis, to develop the unified approach. The obtained information will help us to formulate a proposal for the legal establishment of the right in question not only on a national basis but within international cooperation as well.

Attainment of the study's goals requires the development of recommendations for further improvements in the countries, where the right to know genetic origins is not clearly stipulated, as an exemplar Ukrainian legislation is provided. The changes must help to minimize the gaps regarding this issue in family law and human rights within European counties. As a baseline, we will focus our

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[7] Vardit Ravitsky, "Knowing Where You Come From: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness", *Minnesota Journal of Law, Science & Technology* 11(2), (2010):655-684.

[8] Samantha Besson, Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights, *International Journal of Law, Policy and the Family,* 21(2), (2007): 137-159.

[9] Elodie Decorte, "Donor Conception: From Anonymity to Openness, Plurality and Diversity of Family Relations in Europe" in *Plurality and Diversity of Family Relations in Europe*, Katharina Boele-Woelki and Dieter Martiny (eds.), Intersentia, 2019.

[10] Brigitte Clark, "A Balancing Act? The rights of Donor-Conceived Children to Know Their Origins", *Georgia Journal of International and Comparative Law* 40,3 (2012):620-661.

[11] Jane Stoll, "Swedish donor offspring and their legal right to information" (licentiate thesis, Uppsala University, 2008).

[12] Janne Rothmar Herrman, "Anonimity And Openess In Donor Conception: The New Danish Model", European Journal of Health Law 20, (2013):505-511.

attention on several selected jurisdictions: Sweden, Ireland, Netherlands, United Kingdom, Germany in order to see the difference with less developed jurisdiction in this sphere, particularly Ukraine.

**The objectives of the study** are formulated with the intention to prove the necessity to recognize the right to know one's genetic origins on the legislative level. They are as follows:

(1) to approach the relevant literature, international legal acts and cover the scope of the definition of the right to know one's genetic origins, the right-bearers (stakeholders), as well as moral grounds supporting the necessity of establishing the right to know one's genetic origins;

(2) to study ECHR practice and current legislative provisions within selected European countries regarding establishment the right to information about genetic origins;

(3) to highlight existing problems when it comes to the establishment of the right to know one's origins, develop recommendations, and discuss possible solutions.

In order to achieve the aim and answer on the research question of the master thesis, we will use several **methods** that will help us to find and apply the relevant sources. Particularly, we will use formal dogmatic methods that will be applied in order to identify the legal provisions related to the topic of this paper and understand the significance and meaning of present material. Additionally, we will use examples of legislative regulation in European countries. For the interpretation of the law provisions, we will use hermeneutic methods. We will refer to the main provisions of international acts which will help us to see a broader picture of some issues and understand the background and basis of the right to know one's genetic origins. We will analyze the materials and sources that will help us to interpret the actual situation of the right in question. The additional ground for our evaluations and statements will be the case practice of ECHR because it shows us how the Court interprets norms of the Convention in the light of the right to know one's genetic origins. Further discussion and consideration of the results of the study requires using the general scientific methods of analysis, description, and interpretation. We will also apply the comparative law method. Especially in the present case it will help to observe how the international trends towards the right to know one's genetic origins are developing. From the Ukrainian perspective, it will help to think about possible changes and implementations in the current national legislation using the practice of other countries as guidelines. For this reason, we will use logical-semantic, formal-legal, systematic methods, and, yet again, methods of analysis and synthesis.

**Structurally,** this paper is divided into 3 sections:

1. The scope and content of the right to know one's genetic origins.
2. Enforcing the right to know one's genetic origins: legal framework and court practice.

3. Problematic issues concerning the right to know one’s genetic origin.

**In Chapter 1** we will explore the theoretical background of the right to know one’s genetic origins together with its establishment in international legal acts. At the end of the mentioned chapter, we will be able to formulate a basic understanding of the right in question and realize its importance both from legal and ethical perspectives.

**In Chapter 2** the legislation of European countries will be analyzed**.** For understanding the topical issues, we will take for observation countries which were the first in banning donor anonymity, such as Sweden. Then we will analyze jurisdictions, where these provisions have certain peculiarities, to understand the trends in regulation. To support analysis of legislation, we will review ECHR decisions to find out how the Court understands the scope of the right to know one’s genetic origin and its limitations.

**Chapter 3** will be dedicated to practical issues and main complications. Relevant problems of nowadays will be discussed. Particularly, we will cover the issue of donor anonymity and statements supporting and opposing it. Furthermore, we will explore the complication arising while balancing the rights of parents, children, and third parties. We will discuss whether it is possible to meet the interests of all involved without jeopardizing the rights of each of them. As well we will address other matters which can act as barriers to the right to know, such as ‘reproductive tourism’. In the end we will bring to a discussion potential options to grant the right to know origins taking into account ‘child’s best interest’ and other parties rights.

**The defendant statements** of Master Thesis offered are as follows:

1. Donor-conceived individuals, adoptees, and people with misattributed paternity should unconditionally have a right to know their genetic origins within the scope of the fundamental human rights.
2. There is a duty upon the State to ensure that those people have the possibility to receive information about their origins.
3. There is a need to establish a special, widely used mechanism, which will enable easy and available access for people searching for genetic origins.

# 1. THE SCOPE AND CONTENT OF THE RIGHT TO KNOW ONE'S GENETIC ORIGIN

## 1.1. The scope and approaches to understanding the right to know one's genetic origin.

For many people a question about genetic origins seems so obvious. We are used to the fact that we know family history, we are curios finding the information about our ancestors, we are excited to generate family tree, investigate relative ties and connections between them. However, the human life is so complicated that a set of circumstances can cause that the identities of biological and social parents are not the same individuals. For sure, we can raise this issue when we are speaking about adopted children, who in many cases know that somewhere their biological parents exist but rarely know their identity. Exactly the same is happening when it comes to the use of assisted reproduction technologies (hereinafter – the ART). In this case searching for biological roots does not seem so easy anymore. That is why it is important to realize that all people, regardless the circumstances of their birth, have the right to know their genetic origins.

The use of ART is often the cause of uncertainty in establishing the genetic relations of individuals. The first baby to be conceived via IVF procedure was Louise Joy Brown, who was born at Oldham and District General Hospital in Manchester, England in 1978. The local reports were stating: "the healthy baby was delivered just before midnight by caesarean section and weighed in at five pounds, 12 ounces" (less than 3 kg).[13] This was the beginning of the new era of reproductive technologies. Among several possible options of ART, first sperm and egg donations had been conducted. At those times it was an enormous breakthrough in a brand-new field of reproductive medical science, which gave a big push in further studies and even bigger hope for families coping with different problems such as infertility, genetic incapability of the spouses and so forth. For such cases medical literature provides a term 'third-party reproduction', which refers to involving someone other than individual or couple that plans to raise the child in the process of reproduction. This includes using donated eggs, sperm, embryos and gestational-carrier arrangements, in which the pregnancy is carried by another woman (surrogate motherhood).[14]

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[13] History.com Editors, "World's first "test tube" baby born", HISTORY, Accessed 15 January 2020, https://www.history.com/this-day-in-history/worlds-first-test-tube-baby-born.

[14] "Third-Party Reproduction, A Guide for Patients", American Society for Reproductive Medicine, 2018, Accessed 15 January 2020, https://www.reproductivefacts.org/news-and-publications/patient-fact-sheets-and-booklets/documents/fact-sheets-and-info-booklets/third-party-reproduction-sperm-egg-and-embryo-donation-and-surrogacy/.

Nowadays using the ART is not more a phenomenon but rather a normal procedure, which is widely recognized and suggested for couples willing to have a child. According to the scientific monitorings, since the first IVF baby, in 2018 the number of people conceived by reproductive technologies has grown much faster than it was expected, reaching several millions and approaching 0.1% of the total world population.[15] Together with spreading popularity of ART, new challenges arose in legal-ethical framework as a result of using such technologies. Individuals conceived with the help of genetic material providers (donors) are raised by their social (legal) parents and may or may not know that another person was involved in their conception. While disclosure of the circumstances of conception is highly recommended by professional societies[16] and we will explore it more later on, normally birth certificates do not indicate the involvement of a third-party[17] which puts a burden of decision making strictly on parents.

This situation has caused the creation of tendency in the recognition of the donor conceived individual's right to know genetic origin, taking into account that before this right could be discussed only with regard to the adopted children.[18] In order to understand all these concerns and realize in what ways they could be solved it is necessary to get down to the basic knowledge such as meaning and the scope of the right to know one's genetic origin.

The starting point should be a very short and precise definition of the right to know genetic origin. It is the following: "the right to know one's parentage, one's biological family and ascendance, and one's conditions of birth".[19] Surely, this general definition could be supplemented by other points, such as psychological and social aspects but the main idea is that it is the right to know the information connected with person's private, family life and health condition as well. For this reason, there are various approaches to the definition and justifications of this right brought by bioethics specialists, researchers, lawyers, scientists.

We can highlight main ethical approaches, based on the statements of scientists and psychologists and their arguments showing the existence of a precondition of the right to know about

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[15] Malcolm J Faddy, Matthew D Gosden, Roger G Gosden, "A Demographic Projection of the Contribution of Assisted Reproductive Technologies to World Population Growth", *Reproductive Biomedicine Online* 36 (2018):455, https://www.rbmojournal.com/article/S1472-6483(18)30039-7/pdf.

[16] ASRM (Ethics Committee of the American Society for Reproductive Medicine), "Informing offspring of their conception by gamete or embryo donation: an Ethics Committee opinion", *Fertility and Sterility* 109,4 (2018):601, https://www.fertstert.org/article/S0015-0282(18)30001-3/pdf.

[17] Liza Mundy, "The Strange History of the Birth Certificate", *The New Republic*, February 14, 2013, https://newrepublic.com/article/112375/birth-certificates-age-adoptionand-egg-donation.

[18] K. O'Donovan, "A Right to Know One's Parentage", *International Journal of Law and the Family* 2, (1988):27.

[19] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family*, 21, 2 (2007):137, https://doi.org/10.1093/lawfam/ebm003.

your genetic heritage. The first one is consequentialist, which is explained in the way that "an act can be right or wrong depending on its consequences, so only by empirically assessing and demonstrating harm can we judge the ethically appropriate course of action for donor conceived people".[20] What means that only evaluation of the harm, which the lack of the access to the information about origins has caused, can help to realize the real magnitude of it. The other approach is based on deontological views and is explained as follows: "an act can be right or wrong regardless of its consequences. Knowing one's genetic origins is considered a human right that donor conceived people should have, regardless of empirical evidence".[21]

Similar division of approaches could be found in the bioethics literature with regard to the concept of the right to know genetic origins. Likewise, "the consequentialist approach is based on the notion that lack of such knowledge harms donor-conceived individuals and that such harm can be empirically assessed and demonstrated. The second is conceptual and is based on the idea that knowing is a basic human right and as such no empirical support is required to demonstrate what harm occurs when it is violated". [22]

Vardit Ravitsky combines both approaches and states that individuals have a right to know their genetic origins and consequently, clinical or legal frameworks that its violation is ethically unacceptable and should be modified at both country and international levels. [23] In the past century this issue was raised in United Kingdom in Mary Warnock report, where it was stated "it cannot be argued that children who are told of their origins . . . are necessarily happier, or better off in any way that can be estimated. But I do believe that if they are not told, they are being wrongly treated".[24] We are following this opinion and do support the opinion that no inequality could be created simply for the reason that someone decided to hide the truth about person's origins.

For the purpose of present research, it necessary to provide one more significant approach for understanding this right is human rights approach, which can be outlined while studying case law and international legal acts. Since very active discussions and all further studies concerning the right in

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[20] Vardit Ravitsky, Juliet Guichon, Marie-Eve Lemoine, Michelle Giroux, "The conceptual foundation of the right to know one's genetic origins", *BioNews*, June 5, 2017, https://www.bionews.org.uk/page_96039.

[21] Vardit Ravitsky, Juliet Guichon, Marie-Eve Lemoine, Michelle Giroux, "The conceptual foundation of the right to know one's genetic origins", *BioNews*, June 5, 2017, https://www.bionews.org.uk/page_96039.

[22] Vardit Ravitsky, "The right to know one's genetic origins and cross-border medically assisted reproduction", *Israel Journal of Health Policy Research*, January 16, 2017, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5240377/.

[23] Vardit Ravitsky, "The right to know one's genetic origins and cross-border medically assisted reproduction", *Israel Journal of Health Policy Research*, January 16, 2017, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5240377/.

[24] Mary Warnock, The Good of the Child, 1 *Bioethics* 141, 151 (1987), quoted in Vardit Ravitsky, "Knowing Where You Come From: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness", *The Minnesota Journal of Law, Science & Technology* 11,2 (2010):670,https://scholarship.law.umn.edu/mjlst/vol11/iss2/9.

question are relatively new, it would be reasonable to indicate several directions of its development. Firstly, the right to know one's genetic origins was raised as an outbound of the right to an identity having in mind that this right is a fundamental unalienable human right which allows each individual the ability to enjoy all other rights.[25] Secondly, the right to know one's origins derived from the basic right to information and person's fundamental interest in having access to such an information due to different medical, personal or other reasons. Thirdly, it developed as a derivative form of the right to privacy[26], that we will discuss later in the analysis of provisions of international acts and relevant problems in this regard.

Concerning the first direction, we can make a parallel to the right to personal identity as knowing your genetic origins is crucial for identity formation and the CRC makes an emphasize on the importance of children's identity.[27] As well as Art. 8 of the European Convention on Human Rights states that everyone is granted the right to respect for private and family life, home and correspondence[28] and a significant number of ECHR rulings concluded that the right to identity includes the right to know one' s biological origins and is an integral part of the notion of private life.[29] The second and third directions of the development of the right to know one's genetic origins are tightly linked to each other. It might be an issue that the right to privacy and the right to information could be in conflict because people often view genetic information about themselves as private. People believe that genetic information is strictly confidential and they may decide to keep it in secret. Undoubtedly, they have reasonable grounds to think in this way, especially when it is connected with the information in their medical records. There are three main concepts within privacy issues: confidentiality, security, and anonymity, and each of them important for all individuals. Confidentiality describes a situation in which information is disclosed in a trustful relationship (for example, medical practitioner–patient) on the conditions or legal obligation not to disclose it to a third party without the permission of the provider of such information. Confidentiality, applicable to the nondisclosure of genetic information, is a foundational principle in the ethical codes of many health

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[25] "The United Nations Convention on the Rights of the Child", The Office of the High Commissioner for Human Rights (UN Human Rights), Accessed 10 January 2020, https://www.ohchr.org/en/professionalinterest/pages/crc.aspx.

[26] Manfred Nowak, *UN Covenant on Civil and Political Rights: CCPR Commentary*, 2nd ed., (Germany, Arlington, VA: N.P. Engel Publishers, 2005).

[27] "The United Nations Convention on the Rights of the Child", The Office of the High Commissioner for Human Rights (UN Human Rights), Accessed 10 January 2020, https://www.ohchr.org/en/professionalinterest/pages/crc.aspx.

[28] "The European Convention on Human Rights", European Court of Human Rights, Accessed 15 January 2020, https://www.echr.coe.int/Pages/home.aspx?p=basictexts&c.

[29] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family*, 21,2 (2007):137, https://doi.org/10.1093/lawfam/ebm003.

professions and a key element of a wide range of laws. However, the duty to protect confidentiality is not absolute and in certain circumstances, recognized by law or ethical codes, other interests may be take precedence, such as the safety and health of third parties.[30] Due to the fact that each person's genomes, or full complement of DNA, are unique,[31] the one may decide that he wants to keep information related to that strictly confidential. Nevertheless, the specific variants within an individual's genome may be widely shared with biological relatives or even across the entire human population[32] that is why it is necessary to have access to genetic information as a part of the right to information.

There are several groups of people, who potentially may have an interest to seek for information about genetic origins and may face challenges during the process of getting this information. Samantha Besson defines personal scope of the right to know genetic origins as 'right-bearers'. There are no age limitations towards the person whose interests might be at stake. That means that "the bearers of the right to know one's origins are children as much as adults".[33] Donor-conceived individuals, that means anybody who was born as a result of assisted reproductive technologies using the donation of sperm (sperm donation), ova (egg donation), or embryo donation.[34] Another group – adoptees and all those people who in one or another way are not aware of their parents' personality. This research will refer to both categories of stakeholders.

Alongside it is necessary to indicate options of information, which could be received by interested persons. According to the wider interpretation on this right, it is considered that the offspring can acquire a donor's/birth parent's data, which shows name, gender, date of birth, contact information and other details, which can identify an individual. And in another case, the offspring can receive only non-identifying data, which cannot lead to the disclosure donor's/birth parent's identity. For instance, it can be only medical records or other reports on health condition.[35]

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[30] Ellen Wright Clayton et al., "The law of genetic privacy: applications, implications, and limitations", *Journal of Law and the Biosciences*, 6:1 (2019), https://doi.org/10.1093/jlb/lsz007.

[31] F. Nipa Haque, Irving I. Gottesman, Albert H.C. Wong, "Not Really Identical: Epigenetic Differences in Monozygotic Twins and Implications for Twin Studies in Psychiatry*", American Journal of Medical Genetics, Part C Seminars in Medical Genetics* 151,2, (2009):137.

[32] Ellen Wright Clayton, et al., "The law of genetic privacy: applications, implications, and limitations", *Journal of Law and the Biosciences*, Volume 6, Issue 1, (2019), https://doi.org/10.1093/jlb/lsz007.

[33] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family* 21, 2 (2007):144, https://doi.org/10.1093/lawfam/ebm003.

[34] "Donor Conceived Person", Wikipedia, accessed 15 January 2020, https://en.wikipedia.org/wiki/Donor_conceived_person.

[35] Sonia Allan, "The Release of Identifying and Non-Identifying Information about Donors to Donor Conceived Individuals", *Australian and New Zealand Journal of Obstetrics and Gynaecology* 50 (2019):35.

Considering all the above, we have realized that a general tendency of discussing the right to know one's genetic origins appeared after the extension of popularity of using ART in infertility treatments. The one view of understanding the right to know one's genetic origins is based on the ethical grounds, formulated in the bioethical sources. The difference in their 2 approaches are grounded on the consequences of the absence of the knowledge about origins. Consequentialist one follow the idea that only the evidence of the harm which the person suffers from the impossibility to enjoy the right to know can indicate the necessity of the right itself. While the deontologist or conceptual supports the view that without the reference to the extent of the harm suffers, this right is a basic human right.

In realizing the scope of the right in question we have to refer to the basic understanding of human rights law. As this general understanding shows the aspects, according to which the right can be discussed, particularly 3 directions: as a part of the right to identity, the right to privacy and the right to information.

### 1.2. The special significance of genetic information and ethical justifications that may ground a right to know one's genetic origin.

Before delving into the peculiarities of legislative support of the right to know genetic origins there is a need to discuss the substantiation of existing views regarding this issue. Not surprisingly, the topic is studied more from ethical perspectives. Inmaculada de Melo-Martin, a professor of medical ethics in the Division of Medical Ethics at Weill Cornell Medical College, explored the following dimension from the perspective of donor-conceived individuals. She assures that there is a "need to unveil how arguments defending a right to know one's genetic origins rely on a set of assumptions that are, in themselves, harmful."[36] Also she expressed her concerns towards the disclosure the identity of a person's biological parents. In her opinion the most important is moral aspect rather than a legal one. She supports this argument indicating that three different interests might be protected by different aspects of the right to know one's genetic origins: knowing one's method of conception, access to medically relevant information and access to identifying information about one's genetic parents.[37]

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[36] Kimberly Leighton, "The Right to Know Genetic Origins: A Harmful Value", *Hastings Center Report* 44:2 (2014):5, https://onlinelibrary.wiley.com/doi/pdf/10.1002/hast.334

[37] Inmaculada de Melo-Martin, "The Ethics of Anonymous Gamete Donation: Is There a Right to Know One's Genetic Origins", *Hastings Center Report* 44:2 (2014):29, https://www.academia.edu/6608779/The_Ethics_of_Anonymous_Gamete_Donation_Is_There_a_Right_to_Know_Ones_Genetic_Origins.

Katherine O'Donovan presents similar ideas in her research concerning adoptees by stating that there are three main needs to have this type of information.[38]

> First one is the desire to know one's medical and health history and for this purpose knowing the medical history of one's parents and ancestors becomes important. The second interest is one's legal interest in property, which blood relationship may confer on children. However, these two interests are considered as subsidiary interests. Truly primary interest is the third one - a psychological need for identity. The psychological need to know one's roots or identity is found to be the most important reason as to why adoptees want to know about their biological parents. While medical and legal interest in knowing one's identity may act as contributing factors which motivate an adopted child to know their roots, psychological presence or absence of a member in the relevant network can determine the nature of social interactions that an adolescent will have. [39]

As we can see there is no difference both for donor-conceived and adoptees in the degree of importance of obtaining such information, especially the psychological aspect. For both groups it is crucially important health data as well as strong psychological point and a condition of self-determination in the society.

Justifying the need to know genetic origins, Vardit Ravistdky notes four possible aspects, which affect the needs of people seeking for the information about their genetic parents and each of these aspects is based on a different understanding of the meaning of genetic relatedness.[40] It is reasonable to divide them into 2 groups: medical and socio-ethical. The medical aspect, which points towards the right to know one's full medical history and to know necessary genetic information about the donor. It expresses a narrow understanding of genetic relatedness as important strictly in a biological sense. The identity aspect which refer to the right to personal information about the donor as a person. There she means that not only non-identifying information should be open. This aspect would assist offspring in overcoming identity issues as it expresses a broader understanding of genetic relatedness as having an effect on personal identity. The relational aspect points towards the right to know the full identity of the donor in order to contact him or her and attempt to establish a relationship. Finally, the parental disclosure aspect relates to the right to know the truth about the circumstances of one's conception as a point prevailing parents' right to privacy. It expresses the most sensitive and deep understanding of genetic relatedness, seeing it as creating a strong connection to justify State's

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[38] K. O'Donovan, "A Right to Know One's Parentage", *International Journal of Law and the Family* 2, (1988):27.

[39] K. O'Donovan, "A Right to Know One's Parentage", *International Journal of Law and the Family* 2, (1988):27.

[40] Vardit Ravitsky, "Knowing Where You Come From: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness", *The Minnesota Journal of Law, Science & Technology Volume* 11,2 (2010):665, https://scholarship.law.umn.edu/mjlst/vol11/iss2/9.

interference into the private and family life. [41] We consider such division of aspect as very reasonable and therefore we suggest to examine in detail each of the mentioned above.

### *Medical aspect*

> *"Know your family history, be cognizant of your ethic origin, determine your genetic susceptibilities, opt for necessary gene tests, take preventive actions, establish appropriate surveillance and seek preemptive treatment where applicable. In this way, you can exercise control over your genetic destiny, secure your health, and in more ways than you yet realize – save your life."*[42]
>
> ***Aubrey Milunsky,***
> ***M.D., D.Sc., F.A.C.M.G.***
> ***Founder and Co-Director, Center for Human Genetics, Inc.***

A medical history of person's ancestors consists vital information, especially when it comes to the prevention of certain diseases that may have a genetic link. Nowadays a family health history, also known as a medical genealogy, is no longer limited to a simple desire to trace the family lineage. Healthcare professionals are routinely recommending that patients have to study their family health history due to the fact that geneticists believe that about one-third of all known diseases are connected with genetic preconditions that could be passed to offspring. Nowadays various DNA tests are able to easily determine whether a person carries a gene for many of the leading diseases including cancer, diabetes, heart disease, alcoholism or high blood pressure, among many others.[43]

This aspect of the right to know one's genetic origins is almost the easiest to defend. Denial of the access to medical history and genetic information can cause quite serious harm to health condition, which, in some cases, could be preventable and the interest of an individual in avoiding such harm is strong and clear.[44] And no one will object that avoiding a disclosure of such information could lead to the detrimental consequences.

In the meantime, this aspect is almost the one, where actually there is no need to disclose the identity itself in the meaning of personal data such as name, surname and so forth. As an option, medical centers can provide only records and health outcomes while still keeping the donor's name in secret (only access to non-identifying information). Still there will be a need to observe health

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[41] Vardit Ravitsky, "Knowing Where You Come From: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness", *The Minnesota Journal of Law, Science & Technology Volume* 11,2 (2010):665, https://scholarship.law.umn.edu/mjlst/vol11/iss2/9.

[42] Aubrey Milunsky, *Your Genetic Destiny: Know your Genes, Secure your Health, Save your Life* (Cambridge, MA: Perseus, 2001).

[43] Gary Gilles, "Why You Need to Know Your Family Health History", MentalHelp.net, Accessed 25 January 2020, https://www.mentalhelp.net/blogs/why-you-need-to-know-your-family-health-history/.

[44] Vardit Ravitsky, "Knowing Where You Come From: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness", *The Minnesota Journal of Law, Science & Technology Volume* 11,2 (2010):674, https://scholarship.law.umn.edu/mjlst/vol11/iss2/9.

conditions of donors during the time due to the fact that many illnesses can appear many years after donation.

***Identity aspect***

Vardit Ravitsky explains this aspect as: “the right to have access to information about the donor as a person, information that individuals see as relevant and important to their sense of self. The development of personal identity requires understanding “where you came from” in a sense much broader than knowing the medical implications of the donor’s genetic makeup. It means knowing what the donor is like in ways that would help offspring understand why they are the way they are.”[45] The mentioned above sounds very complicated, however this can help a person to structure his or her tights in the society, link them to cultural, national peculiarities. In other words, to create mentally their own unique place in this world, become a part of society.

From this perspective, “in order to know who, you are, you have to know how you came to be. The understanding of oneself, starting from physical characteristics all the way to personality specifics, talents and interests, is associated with an understanding of where these characteristics came from.”[46] Furthermore,

> the biological aspect of our connection to our past provides a sense of continuity. As we develop a sense of personal identity we constantly refer to “where we come from” as a way of grounding ourselves, establishing a sense of belonging, of our place in the world. Lack of knowledge about the donor as a person could thus create a gap or a void in the formation of personal identity, undermine a sense of continuity and grounding, and lead to troubling and disruptive feelings of incompleteness.[47]

Especially relevant this aspect is for adoptees as many of them grow up already realizing they do not know their birth parents. Hence, they may have a psychological feeling of ‘being lost in society’. Looking through articles with confessions of adoptees, we have noticed that they are using such expressions: “I do not feel like I really belong anywhere”, “I just wanted to know the truth”, “It is not always easy to love your adoptee family”, “…meeting my parents is all I ever wanted…”, “All my life was a lie”.[48] Licensed clinical professional counselor Gelana Mccloud after years of practice

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[45] Vardit Ravitsky, "Knowing Where You Come From: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness”, *The Minnesota Journal of Law, Science & Technology Volume* 11,2 (2010):664, https://scholarship.law.umn.edu/mjlst/vol11/iss2/9.

[46] A. McWhinnie, Gamete Donation and Anonymity: Should Offspring from Donated Gametes Continue To Be Denied Knowledge of Their Origins and Antecedents? *Human Reproduction*, 16:5 (2001):807, https://watermark.silverchair.com/0160807.pdf.

[47] Geraldine Hewitt, “Missing Links: Identity Issues of Donor Conceived People”, *Journal of Fertility Counselling*, 9(3), (2002): 15, https://www.infertilitynetwork.org/files/MissingLinks.pdf.

[48] Gelana Mccloud, “5 Hard Facts about Being Adopted”, Adoptee.org, Accessed 25 January 2020, https://adoptee.org/5-hard-facts-about-being-adopted/.

with highly sensitive child groups made a conclusion that "no one wants to be lied to about who they are or where they came from. In this sense, adoptees are no different. While not all situations are safe for adoptees to know about while young, they eventually need to know. This gives them the opportunity to fill in the blanks with the real information and not leave them guessing".[49]

For adoptees, knowledge about their genetic parents appears to be beneficial, whereas lack of such knowledge can cause psychological problems.[50] The difficulties with formation of identity which adoptees may experience are often described by the term 'genealogical bewilderment'.[51] Adoptees who are deprived of information about their genetic parents can have problems constructing their own unique personal life story, a history that requires information about "those who came before them and those who will follow".[52] It is supposed that the situation of donor-conceived children is in this sense similar: "donor anonymity de facto destroys the child understanding of half of his or her genetic history and about those he or she may regard as their relatives, people sharing something in common. Relying on principles of equal treatment, it is argued that donor-conceived children should be granted the same benefits".[53]

Experts have considered the meaning of identity to be determined by three main aspects: self-definition, coherence of personality and a sense of continuity. Identity is an essential component of member of society and thus seen as "essential component in 'self-in-context'".[54] According to the research from the late 90s, when psychologists Marshall Duke and Robyn Fivush of Emory University in Atlanta, Georgia, asked about 50 families questions about their family history, they found that the more the children knew about their heritage, the stronger was their self-confidence and sense of control over their lives.[55] Therefore, as for the member of the society the right to know genetic roots and ability to study heritage are extremely important.

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[49] Gelana Mccloud, "5 Hard Facts about Being Adopted", Adoptee.org, Accessed 25 January 2020, https://adoptee.org/5-hard-facts-about-being-adopted/.

[50] J. Feast, "Using and not losing the messages from the adoption experience for donor-assisted conception", *Human Fertility* 6,1 (2003):42, https://www.researchgate.net/publication/10832104_Using_and_not_losing_the_messages_from_the_adoption_experience_for_donor-assisted_conception.

[51] H. Sants, "Genealogical bewilderment in children with substitute parents". *British Journal of Medical Psychology* 37 (1964):136.

[52] E. S. Chestney, "The right to know one's genetic origin: Can, should, or must a state that extends this right to adoptees extend an analogous right to children conceived with donor gametes?", *Texas Law Review* 80 (2001):365–391.

[53] E. S. Chestney, "The right to know one's genetic origin: Can, should, or must a state that extends this right to adoptees extend an analogous right to children conceived with donor gametes?", Texas Law Review 80 (2001):365–391.

[54] H. D. Grotevant, et al., "Adoptive Identity: How Contexts within and beyond the family shape developmental pathways", *Family Relations* 49,4 (2000):379, https://www.jstor.org/stable/585833?seq=1.

[55] Rebecca Hardy, "Why children need to know their family history", *The Guardian*, January 14, 2017, https://www.theguardian.com/lifeandstyle/2017/jan/14/children-family-histories-tales.

### ***Relational aspect***

This third aspect of the right to know one's genetic origins is the right to know the identity of the donor in order to make contact and initiate a potential relationship. In our opinion this aspect is closely connected with the identity aspect, however in relational the importance of connections is emphasized more.

"The concept of 'kinship' has traditionally referred to the overlap of a biological and a social relationship. The conventional understanding of kinship is based on the idea of an inherited relationship, one in which a biological and genetic connection permits offspring to inscribe that relationship in their social identity."[56] In this case these biological connections ('blood ties') are a kind of symbolic signs of the relationship. "Genetic ancestry and the desire to either be reunited with or distanced from it, clearly remains significant for people in socio-cultural and psychological sense."[57]

### ***Parental aspect***

Talking about this aspect a subjective factor will play a major role, namely parent's attitude towards revealing the truth about child's origin. We will deal with this aspect again while discussion of problems with disclosure to the child. In one study evidence about rates of disclosure in families that conceived a child with a gamete donation shows that, "despite a shift in professional attitudes toward openness at age of 7, about half of the children conceived by egg donation and nearly three-quarters of those conceived by donor insemination had not been told about their mode of conception".[58] The same thing can be addressed to adopting families. Many psychological barriers usually appear when the parents start to consider a reveling the truth to their beloved child. Today, adoption professionals are closer to a consensus on whether and when to disclose the information to children. The most common recommendation to adoptive parents is to disclose the story of a child's adoption to him or her at a young age, explaining it by the fact that it can be harmful to children's mental health to discover that their parents have lied to them for a significant amount of time. "The thing about late-discovery adoption is, everyone else already knows…" they say. So, when the

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[56] Jennifer Harrington, "Non-reproductive Technologies: Remediating Kin Structure with Donor Gametes", *Science, Technology & Human Values* 33,3 (2008):393, https://www.researchgate.net/publication/249623538_Nonreproductive_Technologies_Remediating_Kin_Structure_with_Donor_Gametes.

[57] A. Diver, *A Law of Blood-ties - The 'Right' to Access Genetic Ancestry* (Switzerland: Springer International Publishing, 2014), 24.

[58] J. Readings et. al., "Secrecy, Disclosure and Everything In-Between: Decisions of Parents of Children Conceived by Donor Insemination, Egg Donation and Surrogacy", *Reproductive biomedicine online* 22,5 (2011):485, https://www.researchgate.net/publication/50376365_Secrecy_Disclosure_and_Everything_In-Between_Decisions_of_Parents_and_Children_Concieved_by_Donor_Insemination_Egg_Donation_and_Surrogacy.

adopted person finds out that parents, grandparents, and even siblings have been consciously withholding information, the discovery can be even more painful.[59]

Several sources indicate that in non-traditional families the rates of disclosure are much higher because of the need to explain the absence of a father in the home.[60]

Another problematic issue of this aspect lays in the attitude of social parents towards donor and towards biological parents of the adoptee by analogy, their willingness to disclose such information. To make it clearer Fiona MacCallum (representative from Department of Psychology, University of Warwick, Coventry, UK) carried out a survey "Embryo donation parents' attitudes towards donors: comparison with adoption", where she made a number of questioners both for embryo donation and adoptive parents. Her conclusion was that the embryo donation parents had less information about genetic parents than did the adoptive parents about the birth parents. That seems logical and obvious. She had explained that it can occur due to the procedures regarding information release followed by the fertility clinics at the time of treatment. Interestingly, the large majority of embryo donation parents did not want to know any more about the donors, particularly, would have been happy with absolute anonymity. Together with little knowledge about genetic parents, embryo donation parents reported significantly less thinking and talking about the donors than adoptive parents did about the birth parents. Parents using ART were grateful to the donors for providing them with the chance to have a child, but their feelings did not go any further. A difference can be noticed in comparison with adoptive parents, who often talked about the birth parents, and noted that they were considering telling truth to the child.[61] Situation when adoptive parents have negative attitude towards birth parents are quite common. They do not see the point for their foster kids to meet biological relatives and often consider it only harmful for the child. Nevertheless, the reality might be different and hiding the information could be even more harmful.

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[59] Asshley Fetters, "What Happens When Parents Wait to Tell a Child He's Adopted", *The Atlantic*, July 22,2019, Accessed 26 January 2020, https://www.theatlantic.com/family/archive/2019/07/adoption-disclosure-study/594496/.

[60] C. Murray, S. Golombok, "Going It Alone: Solo Mothers and Their Infants Conceived By Donor Insemination", *American Journal of Orthopsychiatry* (2005):242; F. Maccallum, S. Golombok, "Children Raised in Fatherless Families from Infancy: A Follow-Up of Children of Lesbian and Single Heterosexual Mothers at Early Adolescence" *Journal of Child Psychology and Psychiatry* (2004):1407 quoted in Tabitha Freeman, Sophie Zadeh, Venessa Smith, Susan Golomboka, "Disclosure of sperm donation: a comparison between solo mother and two-parent families with identifiable donors", *Reproductive Biomedicine Online* 35,5 (2016):592–600, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5084687/.

[61] F. MacCallum, S. Golombok, "Embryo donation families: Mothers' decisions regarding disclosure of donor conception", *Human Reproduction* 22,11 (2007):2888–2895, https://www.researchgate.net/publication/6072704_Embryo_donation_families_Mothers'_decisions_regarding_disclosure_of_donor_conception.

All mentioned before aspects show us that it is crucially important for person to know about genetic origins. Basically, they could be divided into 2 wide categories: medical and socio-ethical aspects, while the socio-ethical in its turn include identity, parental and relational aspects. First of all, a number of health risks may appear if the information about birth parents is in secret. Healthcare professionals are insisting on the recording medical data related to genetic background of the person and highly recommend to share it with the individuals, whose health condition might be at stake. At the same time all other aspects are only boosting a form belief that the knowledge of person's origins plays a significant role in the formation of identity, creation of the feeling that you are a full and equal member of a society.

### 1.3. Approaches under international legal acts

As an integral part of fundamental human rights, the references to the right to know one's genetic origin could be found in several international legal acts. Despite the fact that they do not contain any special rules that would stipulate the right of persons conceived as a result of ART to receive information about their genetic origin.[62] Starting with universal acts dedicated to the protection of human rights in general and following by more specialized, narrowly focused ones.

> The right to know one's genetic origin is usually guaranteed as a negative right that protects one's interests against active violations by state authorities, but also it is guaranteed as a positive right that protects against a lack of action from the state. This positive right can be may be observed when an obligation is imposed on state (in this case an obligation of registering, preserving and opening access to birth data). This is acknowledged by national and international guarantees of the right which protect both its negative and positive dimensions.[63]

Despite the fact that the right to know person's origins is not clearly stipulated in The European Convention on Human Rights (hereinafter – the Convention), straight links could be done from Art. 8, which states:

> 1. Everyone has the right to respect for his private and family life, his home and his correspondence.
> 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country,

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[62] Катерина Москаленко, «Право осіб, народжених із застосуванням допоміжних репродуктивних технологій, на інформацію про своє генетичне походження», *Цивільне право і процес* 1 (2018):29.

[63] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family* 21, 2 (2007):145, https://doi.org/10.1093/lawfam/ebm003.

> for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.[64]

The concept of private and family life also covers the right to develop personal identity and enjoy family rights and ECHR practice shows that the right to know your origins falls within the scope of the conventional right to respect for private and family life. For instance, "Art. 8 of the Convention has been said to protect the right of an adult placed as a child and who has remained in care until adulthood to consult his personal file (*Gaskin v. United Kingdom*), the right of a child to identify her father through DNA testing (*Mikulic v. Croatia*), and the right of an adult to obtain a post-mortem DNA sampling of his father (*Jäggi v. Switzerland*)".[65] Despite the fact that the Court recognizes the right to know origins and states that it is crucially important for individual, there are cases where it could be in child's best interest not to disclose this information. "So far, however, the ECHR has paradoxically rejected the claim that the absolute birth secrecy, granted in some European countries like France, violates Article 8 ECHR and therefore the person was reasonably deprived of her rights to know her mother (Odièvre v. France)".[66]

The same absence of the exact provision granting the right to know your origins in International Covenant on Civil and Political Rights (hereinafter - the Covenant) does not mean that this issue is not regarded in the present act.[67] The provision concerning the right to privacy in Art. 17 states that "no one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honor and reputation. Everyone has the right to the protection of the law against such interference or attacks."[68]

The correlation of the right to know one's genetic origins with the private and family life is addressed on many occasions, which we will discuss later on. Also, the Article 24 of the Covenant grants everyone the right to be registered immediately after birth what is crucial in many respects. It allows the child to become officially recognized in State's records and therefore is a condition for

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[64] "The European Convention on Human Rights", European Court of Human Rights, Accessed 15 January 2020, https://www.echr.coe.int/Pages/home.aspx?p=basictexts&c.

[65] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family* 21, 2 (2007):144, https://doi.org/10.1093/lawfam/ebm003.

[66] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family* 21, 2 (2007):144, https://doi.org/10.1093/lawfam/ebm003.

[67] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family* 21, 2 (2007):141, https://doi.org/10.1093/lawfam/ebm003.

[68] "International Covenant on Civil and Political Rights", The Office of the High Commissioner for Human Rights (UN Human Rights), Accessed 10 January 2020, https://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx.

receiving many public benefits. It also enables the child to find out about her origins later on.[69] Nowadays in all democratic societies this right transformed into the obligation as a person is not considered to exist legally unless he or she obtains official birth registration.

The Human Rights Committee General Comment on Article 24 of the Covenant notes: "this provision should be interpreted as being closely linked to the provision concerning the right to special measures of protection and it is designed to promote recognition of the child's legal personality."[70]

Another international act, the Children's Rights Convention, is described as "the most authoritative legal text on children in international law", stating the primacy and importance of child welfare. This document is emphasizing the child's identity as the key concept of human dignity, and highlights the need to take into account needs, interests, and feelings of children.[71] Besides it indicates the provision concerning the right of the child to know the parents, hence we can make a link to the right to know genetic origin. This fact alone is really important because previously this right to know was not recognized on the level of children's rights.[72]

Article 7 states:

> 1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents.
> 2. States parties shall ensure the implementation of these rights in accordance with their national law and their obligations under the relevant international instruments in this field, in particular where the child would otherwise be stateless.[73]

The CRC has gone on to protect several rights of the child, such as the right to identity that were not recognized as a fundamental human right before. The mere fact of recognition of the right to identity in the CRC shows that international community came to the consensus that this right is worthy of worldwide attention.[74]

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[69] Manfred Nowak, *UN Covenant on Civil and Political Rights: CCPR Commentary*, 2nd ed., (Germany, Arlington, VA: N.P. Engel Publishers, 2005).

[70] "CCPR General Comment No. 17: Article 24 (Rights of the child)", UN Human Rights Committee (HRC), 7 April 1989, Accessed 22 January 2020, https://www.refworld.org/docid/45139b464.html.

[71] A. Diver, *A Law of Blood-ties - The 'Right' to Access Genetic Ancestry* (Switzerland: Springer International Publishing, 2014), 79.

[72] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family* 21, 2 (2007):140, https://doi.org/10.1093/lawfam/ebm003.

[73] "The United Nations Convention on the Rights of the Child", The Office of the High Commissioner for Human Rights (UN Human Rights), Accessed 10 January 2020, https://www.ohchr.org/en/professionalinterest/pages/crc.aspx.

[74] George A. Stewart, "Interpreting the Child's Right to Identity in the U.N. Convention on the Rights of the Child", *Family Law Quarterly* 26,3 (1992):221, https://www.jstor.org/stable/25739908?read-now=1&seq=1#page_scan_tab_contents.

The CRC puts the child's right to identity in a high priority and therefore entitles states to enable it while implementing their policies. This article reflects the idea of the Art. 24 of the Covenant. The Committee on the Rights of Child established by the United Nations has interpreted Art. 7 as "granting a child's right to knowledge of his or her origins. Further, it has consistently criticized nations that do not allow for such a right or that allow mothers to give birth anonymously, as in France, and made recommendations to contracting States Parties regarding incomplete national enforcement of the child's right to know his or her origins".[75]

The mentioned above provision also includes very disputable wording 'as far as possible', which definitely needs a deeper interpretation. It is necessary to distinguish it between different situations.

> The words imply children are entitled to know their parentage if this is possible, even if this is deemed to be against their best interests. But the holistic nature of the Convention suggests that a child who would definitely be harmed by the discovery of his or her parent's identity could be prevented from having this information. This interpretation is supported by the fact that 'as far as possible' also covers the child's right to be cared for by his or her parents – and no one could maintain that 'as far as possible' in that context does not include consideration of the child's best interests. But it is clear that children's right to know their parentage could only be refused on the grounds of best interests in the most extreme and unambiguous circumstances, and children should be given the opportunity for this decision to be reviewed at a later date.[76]

Further, the issue of definition of 'parents' within the scope of Art. 7 remains open as still it is not clear which type of parents are understood within the wording of the provision. It is reasonable to state that this definition should include both genetic and legal parents[77] however the CRC do not indicate a clear understanding of this term within the meaning of the article.

Even though, Art. 7 impose the obligation on states to ensure that information about parents is available to children by all possible means.

Furthermore, the CRC grants children the right to identity with the emphasis on family relations, which is stipulated in Art. 8:

> 1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.

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[75] Brigitte Clark, "A Balancing Act? The rights of Donor-Conceived Children to Know Their Origins", Georgia Journal of International and Comparative Law 40,3 (2012):625, https://digitalcommons.law.uga.edu/cgi/viewcontent.cgi?referer=&httpsredir=1&article=1001&context=gjicl.

[76] "Implementation Handbook on the Convention on the Rights of the Child", UNICEF, accessed 25 January 2020, https://www.unicef.org/publications/index_43110.html.

[77] "Implementation Handbook on the Convention on the Rights of the Child", UNICEF, accessed 25 January 2020, https://www.unicef.org/publications/index_43110.html.

> 2. Where the child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to reestablishing speedily his or her identity.[78]

This provision again put a special emphasis on the identity as a supreme value. It protects against unlawful interference with the recognition of child's identity, including nationality, name and family relations, as part of private life. It also guarantees 'appropriate assistance and protection' in case of situations where children are unlawfully deprived of some or all elements of their identity.[79]

Both mentioned articles of CRC are closely connected with the concept of the best interest of the child. Understanding of this will help to analyze all possible extents in the right to know one's genetic origin later. The problem is that the concept 'best interest of child' is nowhere explicitly defined and it is very complicated to provide an answer whether it is more harmful to children's best interests to give them distressing information about their origins or to refuse them this information on the grounds the information might cause them harm.[80] It is hard to determine a sharp line when a disclosure of biological parents identity will lead to negative consequences and therefore lead to the breach of the concept of 'best interest of child'.

While discussing the CRC provisions in regard to the right to know one's genetic origins, it is worth to mention Art. 13, which grants children "the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print […]".[81] Thus, the information about genetic parents also falls within the scope of this provision and under normal circumstances the child cannot be deprived of this right.

The Hague Convention on Protection of Children and Cooperation in Respect of Inter-Country Adoption prescribes the right to know origins with reference to foster children. Particularly, Art. 30 stipulates:

> 1. The competent authorities of a Contracting State shall ensure that information held by them concerning the child's origin, in particular information concerning the identity of his or her parents, as well as the medical history, is preserved.
> 2. They shall ensure that the child or his or her representative has access to such information, under appropriate guidance, in so far as is permitted by the law of that State.[82]

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[78] "The United Nations Convention on the Rights of the Child", The Office of the High Commissioner for Human Rights (UN Human Rights), Accessed 10 January 2020, https://www.ohchr.org/en/professionalinterest/pages/crc.aspx.

[79] *Handbook on European Law Relating to The Rights of Child* (Luxembourg: Publications Office of the European Union, 2015):68, https://www.echr.coe.int/Documents/Handbook_rights_child_ENG.PDF.

[80] "Implementation Handbook for the Convention on the Rights of the Child: Fully Revised Third Edition", UNICEF, 2007, Accessed 22 January 2020, https://www.unicef.org/publications/index_43110.html.

[81] "The United Nations Convention on the Rights of the Child", The Office of the High Commissioner for Human Rights (UN Human Rights), Accessed 10 January 2020, https://www.ohchr.org/en/professionalinterest/pages/crc.aspx.

[82] "The Hague Convention on Protection of Children and Cooperation in Respect of Inter-Country Adoption", HCCH, 29 May 1993, https://www.hcch.net/en/instruments/conventions/full-text/?cid=69.

Thus, it provides that a child or legal representatives can have access to information relating to her identity, as far as it is permitted by law of the State.[83] That means that mentioned article provide States with an option to decide whether to allow it or not.[84] Further, in the following provision a special emphasis is put on the health aspect concerning this information, particularly the access to medical history.

The United Nations Declaration on Social and Legal Principles Relating to the Protection and Welfare of Children with Special Reference to Foster Placement and Adoption Nationally and Internationally in Art. 9 provides that "there is a need of a foster or an adopted child to know about his or her background should be recognized by persons responsible for the child's care unless this is contrary to the child's best interests".[85] Again, the provision mentions the concept of 'child's best interest'.

Additionally, the European Convention on the Adoption of Children contains a provision which entitles the adoptees the right to know their biological parents. Particularly,

> […] the right to access information held by the authorities concerning his or her origins. Where his or her parents of origin have a legal right not to disclose their identity, it shall remain open to the competent authority, to the extent permitted by law, to determine whether to override that right and disclose identifying information, having regard to the circumstances and to the respective rights of the child and his or her parents of origin. Appropriate guidance may be given to an adopted child not having reached the age of majority.[86]

Considering the fact that the right at issue might also deal with freedom of information or a data subject's rights in data protection law[87], it is worth to mention the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (also known as Oviedo Convention).[88] This Convention is considered to be "the first legally-binding international text created to preserve human dignity, rights and freedoms, through principles

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[83] Jayna Kothari, "The Child's Right to Identity: Do Adopted Children have the Right to know their Parentage?", Accessed 22 January 2020, https://www.cry.org/resources/pdf/NCRRF/NCRRF_ReportBy_Jayna.pdf.

[84] *Handbook on European Law Relating to The Rights of Child* (Luxembourg: Publications Office of the European Union, 2015):69, https://www.echr.coe.int/Documents/Handbook_rights_child_ENG.PDF.

[85] "The United Nations Declaration on Social and Legal Principles Relating to the Protection and Welfare of Children with Special Reference to Foster Placement and Adoption Nationally and Internationally", UN General Assembly, 3 December 1986, Accessed 22 January 2020, https://www.refworld.org/docid/5290a1cf4.html.

[86] "European Convention on the Adoption of Children (Revised)", Council of Europe, Accessed 7 April 2020, https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/202.

[87] Roger Brownsword, Jeff Wale, "The Right to Know and the Right Not to Know Revisited: Part One Asian Bioethics Review", *Asian Bioethics Review* 9,1 (2017), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5585997/.

[88] "Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine", Council of Europe, 4 April 1994, Accessed 22 January 2020, https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/16.

and prohibitions against the misuse of biological and medical advances. Its starting point is that the interests of human beings must come before the interests of science or society".[89] We are referring to it as Chapter III covers the right to respect the private life in relation to the right for information concerning health. In particular, everyone is entitled to know any information collected about his or her health. Taking into account medical aspect of the right to know genetic origin and its impact on the prevention potential health problems, we can make a reference to the provision of the Oviedo Convention.

Considering mentioned before, it is clear that internationally we do not have any integrated definition of the right to know one's genetic origins, neither do we have a clear provision which poses an obligation on State to provide the right to know one's genetic origin unilaterally. The CRC provisions follow the idea that the 'child best interest' must always be prioritizing criteria while deciding on identity issues. While legal acts dedicated to the regulation of adoption procedures provide adoptees with a possibility to have access to information about their origins, still the great weight of decision making in this regard is left to the States.

Generally, we consider that the right in question is provided by the Convention within the scope of broader rights, such as the right to privacy, right to identity, right to information. This position is also supported by the ECHR which raises issues of the need for identity in many of its ruling. Repeatedly, it was stated that the right to know one's genetic origins exists and is crucial for a person and comes along with the right to respect for personal and family life. Further, international conventional framework regarding adoption procedures provides adoptees with the right to information about birth parents and States in their turn are responsible for ensuring that children and their representatives have an access to this data.

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[89] "Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine", Council of Europe, 4 April 1994, Accessed 22 January 2020, https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/16.

## 2. ENFORCING THE RIGHT TO KNOW ONE'S GENETIC ORIGIN: LEGAL FRAMEWORK AND COURT PRACTICE

### 2.1. National legislative acts in European countries.

As we have discussed above, the right to know one's genetic origin is an integral part of fundamental human rights. Nevertheless, the fact of recognition and legal regulation of this right differs from country to country. There are jurisdictions which do not acknowledge the need to grant this right and foremost prioritize the rights of parents and donors (in case of using ART). In other jurisdictions this right is established in legal acts, however the provisions in each of them have certain peculiarities. This kind of discrepancy is connected with the preconditions of disclosure of this sensitive information due to the fact that present issues are very complicated and create the need to take into account a variety of factors, such as type of information to be disclosed, the age, the consent of donor himself, and so forth. Hence, it is important to analyze existing legislative provisions in the European countries in order to figure out in what ways this issue is already regulated and in which direction there is a space for improvement. For the purpose of this chapter of the research we will focus our attention on countries, where the right in question is established on the legislative level.

***Sweden***

Talking about donor-conceived individuals, the first country in Europe which recognized the right to know by abolishing the donor anonymity was Sweden. At the very beginning, legislative changes in the field of ART started with the adoption of the Act *On Insemination* in 1985.[90] Originally, provisions concerning the right to know could be applied only to the cases of sperm donations since egg donations were legalized only in 2003 (when the *IVF Act* came into force). In 2006 both acts were modified, united, and presented as individual chapters of the new *Genetic Integrity Act*[91]. Since that time, this document regulates all activities conducted in relation to the assisted human reproduction and associated research in Sweden, including access to information about donor conceptions.[92]

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[90] Ken Daniels, "The Swedish Insemination Act and Its Impact", *Australian and New Zealand Journal of Obstetrics and Gynecology* 34,4 (1994):437, https://www.researchgate.net/publication/15351461_The_Swedish_Insemination_Act_and_Its_Impact.

[91] "The Genetic Integrity Act (2006:351)", International commission of jurists, accessed 20 February 2020, https://www.icj.org/soginationallegislat/sweden-genetic-integrity-act-2006/.

[92] Jane Stoll, "Swedish donor offspring and their legal right to information" (licentiate thesis, Uppsala University, 2008), 44,https://www.researchgate.net/publication/297916809_Swedish_donor_offspring_and_their_legal_right_to_information.

According to the *Genetic Integrity Act*, information may be required by individuals, conceived after 1st of March 1985 and they have to be 'sufficiently mature'.[93] This wording is not clearly defined and leaves a space for active discussions. By the general rule, 'sufficient maturity' should be considered from the age of majority. However, donor offsprings, who are under 18 years, also have a possibility to search for origins, but firstly they must be evaluated by the Social Welfare Board in order to establish whether or not they are 'sufficiently mature' to know the identity of the donor.[94] In addition, there is nothing stated whether parents and donors have the right to receive the identifying information about each other and whether donors have the right to know the identity of the offspring. Consequently, they do not have the right to get this information under mentioned act.[95] The question of whether the parents of donor offspring should be entitled the right to know the identity of the donor before the offspring is 18 years old was raised by the Insemination Committee in 1983. The verdict was that they could not.[96] Accordingly, it is recommended that only offspring should have the access to this information.

What is more, the impact of child's best interest concept could be observed in the *Genetic Integrity Act*. To explain it Jane Stoll analyzes the provisions: "The requirement to consider the best interests of the prospective child is arguably the cornerstone of the insemination and IVF chapters. The provisions in chapters about insemination and IVF include the statement that donor insemination or IVF may be performed only if it can be presumed that the prospective child will grow up under good conditions".[97]

### *United Kingdom*

United Kingdom is likewise noteworthy example as the discussions concerning problems of donor's anonymity there have started yet over the previous century since the Report of the Committee of Inquiry into Human Fertilization and Embryology (also called the Warnock Report), in which the

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[93] Jane Stoll, "Swedish donor offspring and their legal right to information" (licentiate thesis, Uppsala University, 2008), 45,https://www.researchgate.net/publication/297916809_Swedish_donor_offspring_and_their_legal_right_to_information.

[94] Jane Stoll, "Swedish donor offspring and their legal right to information" (licentiate thesis, Uppsala University, 2008), 45,https://www.researchgate.net/publication/297916809_Swedish_donor_offspring_and_their_legal_right_to_information.

[95] Jane Stoll, "Swedish donor offspring and their legal right to information" (licentiate thesis, Uppsala University, 2008), 46,https://www.researchgate.net/publication/297916809_Swedish_donor_offspring_and_their_legal_right_to_information.

[96] Jane Stoll, "Swedish donor offspring and their legal right to information" (licentiate thesis, Uppsala University, 2008), 46,https://www.researchgate.net/publication/297916809_Swedish_donor_offspring_and_their_legal_right_to_information.

[97] Jane Stoll, "Swedish donor offspring and their legal right to information" (licentiate thesis, Uppsala University, 2008), 44,https://www.researchgate.net/publication/297916809_Swedish_donor_offspring_and_their_legal_right_to_information.

questions of the social impacts of infertility treatment and embryological research were raised. Due to the extreme development in reproduction technologies of that time and a number of contributing factors, like birth of first child through IVF, the need for regulatory works appeared. The Warnock Report included explanations about topical issues cornering infertility, reproductive techniques used and recommendations for future development. Consequently, in 1990 the UK adopted *Human Fertilization and Embryology Act* and established the governmental organization - the Human Fertilization and Embryology Authority (hereinafter - HFEA) in London.[98] This occasion was a starting point of big changes in the shaping of UK legislation.

Even though at that time the *Human Fertilization and Embryology Act* still supported donor's anonymity referring to the potential concerns that the child would reject its legal parents and at the same time fears that the donor can disturb the harmony of the family[99], later on the governmental initiatives started to move towards openness of information about donors.[100]

In 2004 the HFEA introduced the *Regulations on Disclosure of Donor Information.* It included provisions concerning the type of information which exactly could be disclosed. This information can be divided into several groups:

- appearance describing data: the gender, height, weight, ethnic group, eye color, hair color, skin color, year of birth, country of birth and marital status of the donor;
- ethnic background: the ethnic group or groups of the donor's parents;
- health data: the screening tests and information on his personal and family medical history;
- personal data: the donor's religion, occupation, interests and skills; the reason why the donor provided sperm, eggs or embryos;
- identifying data: the surname and forenames of the donor; the last known postal address of the donor; other information regarding appearance of the donor and so forth.[101]

According to the Explanatory Note to the Regulations, the HFEA is entitled to provide the mentioned information on a request of a person over the age of 18 and who was born in consequence

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[98] Jonathan LaTourelle, "The Report of the Committee of Inquiry into Human Fertilization and Embryology (1984), by Mary Warnock and the Committee of Inquiry into Human Fertilization and Embryology", 2014, Accessed 12 February 2020, https://embryo.asu.edu/pages/report-committee-inquiry-human-fertilisation-and-embryology-1984-mary-warnock-and-committee.

[99] I. Turkmendag, R. Dingwall, T. Murphy, "The removal of donor anonymity in the UK: the silencing of claims by would-be parents", *International Journal of Laws, Policy and the Family* 22,3 (2008):285.

[100] L. Frith, "Gamete donation and anonymity. The ethical and legal debate", *Human Reproduction* 16,5 (2001): 818, https://www.researchgate.net/publication/12004061_Gamete_donation_and_anonymity_The_ethical_and_legal_debate.

[101] "The Human Fertilization and Embryology Authority (Disclosure of Donor Information) Regulations", 14 June 2004, accessed 2 February 2020, http://www.legislation.gov.uk/.

of treatment services provided under the *Human Fertilization and Embryology Act* 1990.[102] Depending on the year of donation the information which may be disclosed differs. Anyone who donated before 1 April 2005 is automatically anonymous unless they agreed to change their anonymity status. Anyone who donated after 1 April 2005 has to be ready that their name and last postal address can be disclosed.[103]

The official website of the HFEA (www.hfea.gov.uk) provides detailed information about the possibility to find genetically related persons. Every applicant has to provide only accurate and relevant data. Also the HFEA created a possibility to find genetically related siblings using Donor Sibling Link, a special platform which allows to find siblings from the same donor.[104] For this reason, there is a special application form created for four categories of people:

- donors applying for information about children conceived from their donation. There is a recommendation to use this option after one year after donation just to be sure that the treatment has been performed successfully;
- donor-conceived people applying for information about their donor and potential siblings;
- parents of donor-conceived children applying for information about their donor or siblings;
- donor-conceived people applying to find out if they are genetically related to their partner.[105]

As a step forward, in 2015 UK legalized mitochondrial donations.[106] The status of donors in such donations is different from the ova and sperm donors. This is explained due to the fact that mitochondria are present in almost all human cells, including egg cells, and produce essential energy.[107] As no nuclear DNA of a mitochondrial donor is inherited by a child born following this donation, it is considered that the donor's DNA would have no impact on the physical and personal characteristics of the child. Thus mitochondrial donors remain being anonymous and only limited,

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[102] "The Human Fertilization and Embryology Authority (Disclosure of Donor Information) Regulations", Explanatory note, 14 June 2004, accessed 21 February 2020, http://www.legislation.gov.uk/uksi/2004/1511/contents/made.

[103] The HFEA official website, accessed 20 February 2020, https://www.hfea.gov.uk/ .

[104] The HFEA official website, accessed 20 February 2020, https://www.hfea.gov.uk/ .

[105] The HFEA official website, accessed 20 February 2020, https://www.hfea.gov.uk/ .

[106] "The Human Fertilization and Embryology (Mitochondrial Donation) Regulations" 2015; The HFEA , Mitochondrial donation treatment, accessed 20 February 2020, https://www.hfea.gov.uk/treatments/embryo-testing-and- treatments-for-disease/mitochondrial-donation-treatment/.

[107] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe*, Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 165.

non-identifying information about the donor could be available for the offspring.[108] However, there are arguments supporting the right to know origins after mitochondrial donations. Particularly, an idea of "possible transmission of personal characteristics and the presence of a unique genetic connection by using these donations and the potential harm caused by policies that discourage individuals committed to having genetically related children from pursing mitochondrial transfer is likely to be rather high".[109] Eventually, the dilemma concerning the anonymity in mitochondrial donations exists and should be resolved by further legislative changes.

***Ireland***

The same issue regarding the right to know origins is quite urgent in Ireland right now. It is caused by the fact that the government had already adopted the *Children and Family Relationship Act* in 2015, in which the part 3 is wholly dedicated to the donor-assisted human reproduction.[110] However, this part has not taken action yet.

The relevant data should be recorded in National Donor-Conceived Person Register, particularly:

- the name, date and place of birth and sex of the child;
- the address of the child;
- the information in respect of the parent of the child;
- the information in respect of the donor concerned;
- the date on which the procedure that resulted in the birth of the child was performed;
- the name and address of the procedure facility.[111]

Such a request can be made by child of the age of 18 and in case of younger child – their parents as representatives.[112] Later on people, who attained the age of majority, can apply for a an update of such information.[113]

Additionally, the Act provides the donor with possibility to refrain from the disclosure of their identity but only in exceptional cases, for example when the safety of the releted donor or the donor-

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[108] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe*, Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 165.

[109] R. Brandt, "Mitochondrial donation and 'the right to know'", *Journal of Medical Ethics* 42 (2016), https://jme.bmj.com/content/42/10/678.

[110] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe*, Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 168.

[111] "Children and Family Relationships Act 2015" Part 3 Donor-Assisted Human Reproduction Section 33, The electronic Irish Statute Book (eISB), accessed 18 February 2020, http://www.irishstatutebook.ie/eli/2015/act/9/enacted/en/html .

[112] "Children and Family Relationships Act 2015" Part 3 Donor-Assisted Human Reproduction Section 34, The electronic Irish Statute Book (eISB), accessed 18 February 2020, http://www.irishstatutebook.ie/eli/2015/act/9/enacted/en/html .

[113] "Children and Family Relationships Act 2015" Part 3 Donor-Assisted Human Reproduction Section 38, The electronic Irish Statute Book (eISB), accessed 18 February 2020, http://www.irishstatutebook.ie/eli/2015/act/9/enacted/en/html .

conceived child, or both, requires that this information should not be revealed.[114] Also donors are provided with a possibility to request the information about donor-conceived offsprings.[115]

Additionally, this Act includes a provision about indication a special note in birth certificate of donor-conceived children[116], what shows different approach with the legal framework in European countries.

Another draft act in Ireland which relates the procedures of ART was introduced as the *Assisted Human Reproduction Bill* and was published in 2017.[117] However, the final version of it is still under consideration.

A question of adoptees was not left apart as Irish legislators has initiated act which could provide a possibility to get information about genetic origins. It was *Adoption (Information and Tracing) Bill*, introduced in 2016, according to which "birth records should be given to the adopted person, including those illegally adopted, with the consent of their birth parent. Without any consent, records will only be released if an adopted person signs a statutory declaration not to contact their birth parent and once the legislation has been in place for a year."[118] At this moment, the mentioned act has not come into force yet.

***Netherlands***

The Kingdom of the Netherlands was also among the first countries in Europe, that abolished donor's anonymity. Prior to this, all parents had a possibility to choose the status of their child's donor: it could be either anonymous donor or known donor.[119] In 2004 *The Artificial Conception Donor Data Act* (Wet donorgegevens)[120] changed all the regulations concerning donors and established the Foundation for Donor Information. Since then, everyone who uses ART with donated genetic material is required to report medical, non-identifying and identifying information to this Foundation after

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[114] "Children and Family Relationships Act 2015" Part 3 Donor-Assisted Human Reproduction Section 35, The electronic Irish Statute Book (eISB), accessed 18 February 2020, http://www.irishstatutebook.ie/eli/2015/act/9/enacted/en/html .

[115] "Children and Family Relationships Act 2015" Part 3 Donor-Assisted Human Reproduction Section 36, The electronic Irish Statute Book (eISB), accessed 18 February 2020, http://www.irishstatutebook.ie/eli/2015/act/9/enacted/en/html .

[116] "Children and Family Relationships Act 2015" Part 3 Donor-Assisted Human Reproduction Section 39, The electronic Irish Statute Book (eISB), accessed 18 February 2020, http://www.irishstatutebook.ie/eli/2015/act/9/enacted/en/html .

[117] General Scheme of the Assisted Human Reproduction Bill,2017, Department of Health, Accessed 16 March 2020, https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint_committee_on_health/reports/2019/2019-07-10_report-on-pre-legislative-scrutiny-of-the-general-scheme-of-the-assisted-human-reproduction-bill_en.pdf.

[118] "Ireland to allow adopted people to get their birth records for first time", *The Guardian*, July 28, 2015, https://www.theguardian.com/world/2015/jul/28/ireland-to-allow-adopted-people-to-get-their-birth-records-for-first-time.

[119] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe*, Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 155.

[120] "Wet donorgegevens kunstmatige bevruchting" ("The Artificial Conception Donor Data Act"), Overheid.nl, accessed 19 March 2020, https://wetten.overheid.nl/BWBR0013642/2020-03-19.

experiencing such procedure.[121] That created a potential possibility for donor-conceived offsprings to seek for their origins.

Elodie Decorte cites provisions of the mentioned act, explaining the process of making a request for information about origins and other peculiarities. Particularly, she writes: "Anyone who knows or suspects that he or she is donor-conceived can address the Foundation for information. The donor-conceived child does not have to prove why he or she suspects that he or she has been donor-conceived. Obviously, the Foundation has to verify whether it is correct. For that reason the child needs to attach certain information to the application form (for example a copy of the birth certificate)."[122]

Contrary to Swedish provisions, Dutch law clearly states the age of a person who is seeking for the information about genetic origins and, interestingly, there are certain limitations in the type of information, which person can receive depending on the age (we discussed similar model in the UK[123]). Starting from 12 years the person can receive only non-identifying information about the donor. Such information will be delivered to the address of requesting person without notifying the donor. If the child is younger than 12, then parents are entitled the right to file a request on behalf of their child. From the age of 16, identifying information about the donor can be released with prior notification of the donor.[124] It means that, in fact, the donor can prevent the disclosure of his or her personal details. However, at the same time the Foundation has to balance 'the best interest of a child' and only in exceptional circumstances the interests of the donor should be paramount. The burden of proof lays on the donor. It is up to the donor to show that his or her interests are so important that the release of his or her personal details is not appropriate and that his or her interests take precedence over the consequences that hiding of this information would have for the child. The interests of social parents are not taken into account at all in this case.[125]

If the Foundation decides that the donor's identity should be revealed, despite the donor's refusal, the donor will be informed about this decision and also the donor has a possibility to file an

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[121] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe,* Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 156.

[122] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe,* Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 157.

[123] The HFEA official website, accessed 20 February 2020, https://www.hfea.gov.uk/ .

[124] "Wet donorgegevens kunstmatige bevruchting" ("The Artificial Conception Donor Data Act"), Overheid.nl, accessed 19 March 2020, https://wetten.overheid.nl/BWBR0013642/2020-03-19 quoted in Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe,* Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 157.

[125] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe,* Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 157.

appeal. As long as the time limit for objection or an appeal has not expired, no identifying information will be released. Today, it is still unclear what should stand for an acceptable reason for refusing access (there are presumptions that it could be when donor serving a prison sentence, a donor with a severe mental illness or a donor who was very young at the time of the donation and for whom a confrontation with his past will present insurmountable problems because of his changed family situation and so forth). Changing one's mind about donating cannot be considered to be a reasonable argument.[126]

***Germany***

For many years Germany was considered as a country with not well developed legal regulation in the field of ART: donor sperm and donor embryos[127], considering the fact that egg donation is illegal at all (according to *Germany's Embryo Protection Act* 1990).[128] Germany made significant changes in rules of donor's anonymity and enforcing the right to know the origins not that long ago. In 2017 parliament adopted a *Sperm Donor Register Act*, which established a central register at the German Institute for Medical Documentation and Information (Deutsches Institut für Medizinische Dokumentation und Information (DIMDI)). DIMDI is responsible for storage of registry data for 110 years, and after it will be deleted. All relevant information will be gathered and recorded in the Sperm Donor Register. What makes the mentioned act different on the international background is that its provisions encourage donors to provide supplementary information for offsprings, such as more detailed information about his motivation to donate and the list is not limited.[129]

Together with the mentioned act, the German Civil Code includes certain related provisions. Art. 1600 of the Civil Code states that in the case of medically assisted donor insemination, the "sperm donor cannot become the legal father of the resulting child".[130] This is how the donors are protected against future claims for paternity.

Also earlier, in the case, where the plaintiffs, who were born in December 1997 and February 2002, asked the reproductive clinic for information about the identity of their biological father,

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[126] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe*, Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 157.

[127] Claudia Brügge, Petra Thorn, "How Germany's new Sperm Donor Registry Act is internationally progressive", Bionews, accessed 22 February 2020, https://www.bionews.org.uk/page_96069 .

[128] " Embryonenschutzgesetz – ESchG" ("Germany's Embryo Protection Act"), Federal ministry of Justice and Consumer Protection, accessed 19 March 2020, http://www.gesetze-im-internet.de/eschg/BJNR027460990.html.

[129] Jenny Gesley, "Germany: Right to Know Biological Father for Children Conceived Through Sperm Donation", Library of Congress, accessed 19 February 2020, https://www.loc.gov/law/foreign-news/article/germany-right-to-know-biological-father-for-children-conceived-through-sperm-donati.

[130] Claudia Brügge, Petra Thorn, "How Germany's new Sperm Donor Registry Act is internationally progressive", Bionews, accessed 22 February 2020, https://www.bionews.org.uk/page_96069.

German Federal Court ruled that “a child who has been born through an ART can in principle request information from the clinic about the identity of the anonymous sperm donor”.[131] It was stated that the child interest must outweigh in providing information. Additionally, the court clarified the age limitations and stated that in practice, younger children also have a possibility to receive the information about their origins through their parents, who will file a request as their representatives.[132]

Referring to the adoption procedures in Germany, no information on the fact that the child has been adopted may be revealed without the consent of adoptive parents and the adoptee, nor may the facts regarding the adoption be investigated. This principle also applies to all pre-adoption procedures. The birth certificate of the adopted child shall state only adoptive person as a parent. However, the strict secrecy rule has been softened for the adoptees.[133] The German Federal Constitutional Code has held that each person has a constitutional right to know his or her own biological origins. [134] Thus, a person in the age 16 or over may access the public register, which keeps information on his or her origin and may also see his or her adoption files.[135]

Summing up, provided above examples show options, which selected European countries has chosen as a way to grant the right to know one’s genetic origins. We have studied the mechanisms which they use, particularly: creating special authorities and institutions responsible for maintaining donor registries; providing access to these registries by to filling requests for getting the information concerning donors; setting minimum age requirements for the potential seekers of information. Interestingly, the age eligibility differs from country to country but the common idea is that after the age of majority person can have access to information. They can receive a limited set of identifying information, such as donor’s name, date of birth and contact details. Additionally, the amount of requested information could be directly dependent on the exact year of the donation. In some countries even younger children can obtain this data with the help of their parents, who can make a request for such information, but in Sweden parents are not granted with such possibility.

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[131] “BGH, Urteil vom 28.01.2015 - XII ZR 201/13”, accessed 19 February, https://openjur.de/u/757763.html.

[132] “BGH, Urteil vom 28.01.2015 - XII ZR 201/13”, accessed 19 February, https://openjur.de/u/757763.html.

[133] “Overview of German adoption law”, Center for Adoption Policy, accessed 20 November 2020, http://www.adoptionpolicy.org/ .

[134] Decision of German Federal Constitutional Court BVerfGe79 quoted in “Overview of German adoption law”, Center for Adoption Policy, accessed 20 November 2020, http://www.adoptionpolicy.org/ .

[135] “Overview of German adoption law”, Center for Adoption Policy, accessed 20 November 2020, http://www.adoptionpolicy.org/ .

## 1.2. The recognition of the right to know one's genetic origin in Ukrainian legislation.

Along with the progressive legislations which nowadays are following a clear position concerning the right to know, there are many countries that are only starting their way in the development of legal regulation in this field. We will study the case of Ukraine, where, despite the fact that some legislative provisions foresee the possibility to receive information about biological parents, they are in contradiction with other laws.

The reality is that there is no explicit approach to legislative regulation in the field of ART. The first IVF in Ukraine was performed on November 30, 1984, but the first baby was born only in 1991.[136] According to the statistical data, the last few years the condition of reproductive health in Ukraine is far beyond international standards and is characterized by a low birth rate in addition to the high level of difficulties in reproduction facilities - infertility, stillbirth, spontaneous abortion, birth defects, maternal, perinatal and infant mortality.[137] Due to this fact the ART in Ukraine is in a high demand nowadays.

The first act, which legalized the use of ART in Ukraine, was the Law *On Fundamentals of the Legislation of Ukraine on Health Care* (Закон України «Основи законодавства України про охорону здоров'я» від 19 листопада 1992 року).[138] According to Art. 48 of the mentioned law, the application of artificial insemination and implantation of the embryo is carried out in accordance with the conditions and procedure established by the Ministry of Healthcare of Ukraine. This procedure is done at the request of the woman with the written consent of the spouse, ensuring the anonymity of the donor and maintaining medical secrecy. Disclosure of the donor identity shall be conducted in the way prescribed by law.[139] Since that period the legislator created a potential possibility of revealing of donor's identity. However, the law did not include any further provisions which shall clarify it and establish the concrete procedure of such a disclosure.

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[136] Мусієнко А.В., Дахно Ф.В. "Сучасні репродуктивні технології: досягнення та перспективи в розвитку лікування безпліддя", *Педиатрия, акушерство, гинекология* 18,1 (2007):81, http://health-ua.com/article/17246-suchasn-reproduktivn-tehnolog-dosyagnennya-ta-perspektivi-rozvitku-v-lkuvan.

[137] "Щорічна доповідь про стан здоров'я населення, санітарно-епідемічну ситуацію та результати діяльності системи охорони здоров'я України. 2017 рік", МОЗ України, ДУ «УІСД МОЗ України» (Київ : МВЦ «Медінформ», 2018), 82.

[138] Основи законодавства України про охорону здоров'я: Закон України від 19 листопада 1992 року № 2801-XII", Інформаційно-пошукова система "Законодавство України", accessed 26 February 2020, https://zakon.rada.gov.ua/laws/show/2801-12.

[139] Основи законодавства України про охорону здоров'я: Закон України від 19 листопада 1992 року № 2801-XII", Інформаційно-пошукова система "Законодавство України", accessed 26 February 2020, https://zakon.rada.gov.ua/laws/show/2801-12.

Conversely, *The Order for the usage of assisted reproductive technologies in Ukraine* approved by the Ministry of Healthcare of Ukraine (Порядок застосування допоміжних репродуктивних технологій в Україні, затверджений Наказом Міністерства Охорони Здоров'я від 09.09.2013)[140] does not provide any options for the disclosure. The chapter 5 explains the procedure of the donation of gametes and embryos, where it is stipulated that the use of embryo donation is carried out due to medical indications with the written consent of the patients, ensuring donor anonymity and keeping medical confidentiality.[141] Therefore, we can conclude that, according to this act, donors, remain anonymous and two mentioned acts do not have a unity concerning the question of donor secrecy in ART.

In addition, the right to use ART is established by the Art. 281 para 7 of the Civil Code of Ukraine, which states that woman or men in the age of majority is entitled to medical treatment for assisted reproductive technology treatment programs in the way prescribed by law.[142] Art. 290 states that the donor's identity should not be known to the recipient and the recipient's identity to the donor's family, unless the recipient and the donor are married or have close relatives.[143] These provisions apply to all medical treatments, which are conducted with involvement of donors, so that ART falls within the scope. Hence, the Civil Code recognizes the right to know the identity of donor only in the exceptional case.

Taking into account the current trends in democratic societies towards openness, the necessity to establish an effective legal framework in the field of reproductive technologies in Ukraine is crucially important. The State shall meet the human right standards established by the Convention, in this case, provision of Art.8 of the Convention. Furthermore, "by ratifying the CRC, States Parties commit themselves to protecting and ensuring children's rights and developing actions and policies to promote the best interests of the child".[144]

As a part of the legislative changes in this field, Ukrainian Parliament (Верховна Рада України) released several draft laws regarding reformation of the ART legal framework. One of those

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[140] "Наказ МОЗ України Про затвердження Порядку застосування допоміжних репродуктивних технологій в Україні від 09.09.2013", Інформаційно-пошукова система "Законодавство України", accessed 26 February 2020, https://zakon.rada.gov.ua/laws/show/z1697-13?lang=uk.

[141] "Наказ МОЗ України Про затвердження Порядку застосування допоміжних репродуктивних технологій в Україні від 09.09.2013", Інформаційно-пошукова система "Законодавство України", accessed 26 February 2020, https://zakon.rada.gov.ua/laws/show/z1697-13?lang=uk.

[142] "Civil Code of Ukraine", accessed 26 February 2020, https://zakon.rada.gov.ua/laws/show/435-15.

[143] "Civil Code of Ukraine", accessed 26 February 2020, https://zakon.rada.gov.ua/laws/show/435-15.

[144] Brigitte Clark, "A Balancing Act? The rights of Donor-Conceived Children to Know Their Origins", *Georgia Journal of International and Comparative Law* 40,3 (2012):625, https://digitalcommons.law.uga.edu/cgi/viewcontent.cgi?referer=&httpsredir=1&article=1001&context=gjicl.

was a draft of The Law of Ukraine *On  Assisted Reproductive Technologies (Закон України «Про допоміжні репродуктивні технології»)*.[145] According to it, the donor can be a woman (18 – 35 years) or man (20-40 years) if she/he has own born child without birth defects. Also there cannot be any medical contraindications for donation and the donor has to undergo a medical examination. Taking into account the general rule, the donor remains anonymous, however the law mentions the possibility of being a non-anonymous donor.  Art. 13 states that determination of the child's origin born as a result of using ART is performed according to the provisions of Family Code of Ukraine, which we will discuss down the line.  All the information regarding the procedure of ART as a whole and donor's data should have a status of confidential information and medical secrecy. Further the draft law contains similar to German provisions which protects the donor from the potential legal relationship with the offspring. Namely, after successful donation and birth of the child, donors do not acquire parental rights and responsibilities with respect to their offspring, nor are they entitled to determine the fact of the birth and the person's social parents.[146]

Due to the immediacy of the following problem, the mentioned draft law was actively discussed among the members of parliament which lead to the proposal of another draft: The Law of Ukraine *On Assisted Reproductive Technologies as an alternative to the Law No 8629*[147] (the one which was highlighted above). This alternative includes an interesting provision concerning conditions of anonymity, namely the placing of donor's database with their photo cards is not considered as a violation unless donor did not give consent for that and the system is not logically protected. Hence, we can see the mention of the donor's database, however there is no explicit information regarding it.

Both draft laws were dismissed by Ukrainian Government in August 2019. The reasoning was published by the Committee of Parliament of Ukraine (Верховна Рада України) in the conclusion, which stated that both documents contain technical and legal deficiencies and a number of regulations that are contrary to the current legislation, also they do not meet requirements of international standards, set in the Oviedo Convention, which was signed by Ukraine in 2002 but have not been

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[145] Проєкт Закону України від 19.07.2018 № 8629 «Про допоміжні репродуктивні технології», accessed 27 February 2020, https://ips.ligazakon.net/document/JH6NP00A.

[146] Проєкт Закону України від 19.07.2018 № 8629 «Про допоміжні репродуктивні технології», accessed 27 February 2020, https://ips.ligazakon.net/document/JH6NP00A.

[147] Проєкт Закону України від 01.08.2018 № 8629-1 «Про допоміжні репродуктивні технології, як альтернативний до реєстр. N 8629» accessed 27 February 2020, http://search.ligazakon.ua/l_doc2.nsf/link1/JH6NP1AA.html.

ratified yet.[148] It lead to the conditions that the attempts to change ART regulations were suspended and at this moment there are no new alternatives yet.

At the same time Family Code of Ukraine includes a special norm of parenthood determination for the donor-conceived children, which says that if donor concessions were performed with a written consent of a husband, he is considered as a father in legal sense. If it comes to the spouses, whose biomaterial was used for an embryo which later was transferred to another woman this spouse is considered as parent. The same will be in the case, when only husband's biomaterial is used for another woman.[149]

While analyzing the gaps in the current Ukrainian legislation, Kateryna Moskalenko mentions the necessity of the adoption of completely new law on ART, which should specify the conditions for disclosing the identity of the donor while taking into account children rights and interests of donors and parents.[150]

Considering all mentioned before, we agree that currently Ukrainian legislation does not include a clear provision which entitles the donor-conceived individuals with the right to information about their genetic heritage. While the proposed draft laws contained several essential ideas for reformation of ART legislation, still they need further considerations. Particularly, concerning the right to know the following steps could be done:

- clarifying the personal scope of the right;
- establishment a special donor registry which is responsible for gathering and storage of this information;
- creation of the institution responsible for the maintenance of registry;
- specifying which type of information could be disclosed and conditions which should be met in order to have access to the information;
- establishment a progressive international cooperation in the field of ART.

The situation with adoptees is not less complex. In Ukraine the vast majority of norms is devoted to the secrecy of adoption while the children's right to know their parents still has a lot of

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[148] Висновок до проєкту Закону України від 23.04.2019 № 8629 «Про допоміжні репродуктивні технології», Ліга закон, accessed 13 March 2020, https://ips.ligazakon.net/document/XH6NP00Q?an=4.

[149] «Сімейний Кодекс України», Законодавство України, accessed 28 February 2020, https://zakon.rada.gov.ua/laws/show/2947-14.

[150] Катерина Москаленко, «Право осіб, народжених із застосуванням допоміжних репродуктивних технологій, на інформацію про своє генетичне походження», *Цивільне право і процес* 1 (2018):29.

gaps. Therefore, a practical and theoretical problem arises while ensuring the realization of the mentioned right.[151]

The Family Code focuses on ensuring that the child has the right to information about his or her own parentage at the time of adoption. The adopted child at the age of 14 is entitled the right to receive information about the adoption.[152] However, a contradiction with another provision appears directly due to the fact that adopter has a right to hide the fact about the adoption from the child, even after reaching the age of majority, and the right to require the other persons to conceal the adoption.[153]

Another issue is that it is still not clear which type of information could be revealed even if the provision sets the right to have access to this information. The wording of the article says exactly ‘information about adoption’. Thus, it is not clear what information the child may receive: from the preparatory stage of adoption, or long before it, or from the moment of adoption. And what kind of information should it be? Only a personal data of their biological parents, reasons for rejection by parents, the presence of other relatives, her former residence, the data of officials who performed certain official functions during the adoption process, etc. Which public authority should be responsible for recording and providing this information?[154] The scholars who were working on this topic formulated different approaches towards the understanding which type of information could be revealed. For example, there is an opinion that the child has the right to receive any information regarding his or her adoption.[155] Another view supports the idea that an adopted child is entitled to receive only the information and documents relating to the procedure of adoption.[156] Those in the present situation all these issues remain unsettled.

Even more legal uncertainty appears in the Article 226 of Family Code of Ukraine which mentions the secrecy of adoption. Particularly, the provision states that adopted child has this right, including the secrecy from the child himself.[157]

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[151] Мельник О., “Право дитини на інформацію про власне походження”, *Часопис цивілістики* 20, 2016):132.

[152] «Сімейний Кодекс України», Законодавство України, accessed 28 February 2020, https://zakon.rada.gov.ua/laws/show/2947-14.

[153] «Сімейний Кодекс України», Законодавство України, accessed 28 February 2020, https://zakon.rada.gov.ua/laws/show/2947-14.

[154] Мельник О., “Право дитини на інформацію про власне походження”, *Часопис цивілістики* 20, 2016):132.

[155] Король И. Г. *Личные неимущественные права ребенка* (автореф. дис. на соискание науч. степ. канд. юрид. наук спец. 12.00.03, гражданское право; предпринимательское право; семейное право; международное частное право, Москва, 2008б с.26) quoted in Мельник О., “Право дитини на інформацію про власне походження”, *Часопис цивілістики* 20, (2016);132.

[156] Темникова Н. А. “*Реализация и защита личных неимущественных прав ребенка в семейном праве России*” (автореф. дис. на соискание науч. степ. канд. юрид. наук спец. 12.00.03б Омск, 2006, с.26) quoted in Мельник О., «Право дитини на інформацію про власне походження», *Часопис цивілістики*, 20, (2016):132.

[157] «Сімейний Кодекс України», Законодавство України, accessed 28 February 2020, https://zakon.rada.gov.ua/laws/show/2947-14.

To sum up, the Ukrainian legislators took into account the need to establish the right to information about child's origin only with regard to adoption procedure. Still the complications of ensuring the child's right to information about his or her parents remains unresolved in the case of using ART. There is no specific rule in national law indicating a child's right to obtain the information about genetic origin and providing a mechanism for exercising such right.

### 2.3 European Court of Human Rights: case law overview and analysis.

The European Convention on Human Rights and Fundamental Freedoms "has long been regarded as one of the key instruments in human rights law, especially given its capacity to act as a 'living instrument' that continually evolves to reflect social and cultural changes".[158] The main aim of the Convention is to create a mechanism for ensuring the adherence of the rights and freedoms prescribed by it. First and foremost, it is crucially important to the recognize the right in question within the scope of the conventional right to respect of private and family life. Particularly, the mentioned right is declared as "an integral part of the right to respect for private life"[159] and ECHR rulings has repeatedly emerged the right to know one's genetic origin within the scope of Art.8 of the Convention. On this matter Samantha Besson states: "Article 8 of the Convention expressly recognizes the possibility of restricting the right to know one's origins when it conflicts with other rights. It also provides the conditions that need to be respected and hence some balancing guidelines. These are legality, the existence of rights or interests of others and proportionality. One usually adds a fourth condition, the respect of the right's inner core".[160]

In almost all cases the Court acknowledges the importance of knowing the 'biological truth' despite the different outcome of decisions. At the same time, the Court leaves a wide margin of appreciation in this point upon the States.[161] The largest share of the reasoning is devoted to the explanation of the concept of child's best interest and its role in recognizing the right to know genetic origins.

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[158] "Tyrer v. United Kingdom, Application no. 5856/72, judgment of 25 April 1978" para 31, HUDOC, accessed 15 January 2020, http://hudoc.echr.coe.int/eng?i=001-57587 quoted in A. Diver, *A Law of Blood-ties - The 'Right' to Access Genetic Ancestry* (Switzerland: Springer International Publishing, 2014), 104.

[159] Ursula Kikelly, "The right to respect for private and family life. A guide to the implementation of Article 8 of the European Convention on Human Rights", accessed 30 March 2020, https://rm.coe.int/168007ff47.

[160] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", *International Journal of Law, Policy and the Family*, 21,2 (2007):151, https://doi.org/10.1093/lawfam/ebm003.

[161] Samantha Besson, "Enforcing the child's right to know her origins: contrasting approaches under The European Convention on Rights of Child and The European Convention of Human Rights", International Journal of Law, Policy and the Family, 21,2 (2007):151, https://doi.org/10.1093/lawfam/ebm003.

It should be noted that the Court does not establish an absolute understanding of the right to know origins and how it should be recognized. In most cases the concept of child's best interest and a balance between parent-children rights prevails.

There are a set of classical examples of decisions which the position of the Court regarding the right to know. In the case *Gaskin v. UK*, the applicant Graham Gaskin faced challenges when attempting to find information about his childhood in care. However, local authorities refused to provide him with this details referring to the defense of public interest. After exhaustion of possible domestic remedies, the applicant took legal action in ECHR. Here the Court again supported the position of applicant, stating that "information contained highly personal aspects of the applicant's childhood, development and history and thus could constitute his principal source of information about his past and formative years".[162] Hence, the violation of Art. 8 took place unquestionably. However, the core of this violation laid not in the fact of wrongful actions of the State but rather in the failure to act.[163] The State simply did not comply with its positive obligation to ensure Art. 8 of the Convention.

All literature related to the discussion of the right to know one's genetic origin cites the well-known ECHR ruling *Odievre v. France*.[164] Due to the factual circumstances of the following case, biological mother abandoned the applicant, Pascal Odievre, right after the birth and left a written statement that she wants to keep the fact of birth in secret. Later on the applicant requested for the disclosure of information about her birth and potential siblings. However, the authorities rejected this request relying on the fact that it will contradict to the existing laws concerning anonymous birth. France is known for its system of giving birth under complete anonymity. In this context the issue about the violation of the right to respect of private and family life arose before the Court. The applicant argued that the legislation literally deprived her from a possibility to find out truth about her blood ties and prevented from the access to information about personal history. In her statements Pascal mentions the psychological challenges she had to face due to the impossibility to find out the truth: "how difficult it was for her to live without knowing her original identity and complained not only of the arbitrary interference in her life as an ordinary citizen caused by the system used to preserve confidentiality, but also of culpable failure on the part of the domestic authorities through their refusal

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[162] "Gaskin v. UK, Application No 10454/83, judgment of 7 July 1989", Para36, HUDOC, accessed 15 January 2020, http://hudoc.echr.coe.int/eng?i=001-57491.

[163] "Gaskin v. UK, Application No 10454/83, judgment of 7 July 1989", Para 49, HUDOC, accessed 25 January 2020, http://hudoc.echr.coe.int/eng?i=001-57491.

[164] "Odievre v. France, Application no. 42326/98 Judgment of 13 February 2003", HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-60935.

to disclose the requested information even though it was available in the file".[165] The applicant alleged on the fact that the State infringed her right to private life, particularly the possibility to find the information about her birth mother. She believed that she was deprived of this possibility because an existing unreasonable presumption in society that "children without a past are easier to adopt".[166] Explaining the emotional side of the process, she states that "an understanding by the adoptive parents of their child's desire to know his or her natural parents and support for him or her in that quest could only serve to strengthen it".[167] This expressions prove how emotionally difficult it is for people to go through the process of 'fighting for the truth about birth parents'. And from this point of view the Court supported the applicant, mentioning "the vital interest, protected by the Convention, in receiving the information necessary to know and to understand their childhood and early development".[168] However, the Court emphasized on the two sides of the scope of the right to privacy and respect for private life. In the present case it was both child's interest to know origins and mother's interest to remain anonymous, where the goal of the Court was "not to judge that conduct, but merely to take note of it".[169] Consequently, it was noted that it is up to the discretion of the State to decide upon the balancing the interest of birth mother and born child. Hence, such sensitive issues should be decided by the State and here was no violation of Art. 8.

Several judges did not support the Court's positioning in this and they expressed it in the dissenting opinion. They argued that the question of applicant's private life was not explored enough. A fair balance was not maintained due to the mere fact that "the right to access to information about one's personal origins ultimately remained within the mother's sole discretion". Also it was concluded that "adopted children often consider it their duty to trace their original parents. Even if it has been adopted, a child who is unable to gain access to any type of information about its family origins is made to endure a form of suffering, and that suffering may leave scars".[170]

Rather different approach was showed by the Court in *Jaggi v. Switzerland* case. The situation was different as the biological father of the applicant passed away and there was a need to perform a

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[165] "Odievre v. France, Application no. 42326/98 Judgment of 13 February 2003", Para 30, HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-60935.
[166] "Odievre v. France, Application no. 42326/98 Judgment of 13 February 2003", Para 32, HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-60935.
[167] "Odievre v. France, Application no. 42326/98 Judgment of 13 February 2003", Para 32, HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-60935.
[168] "Odievre v. France, Application no. 42326/98 Judgment of 13 February 2003", Para 42, HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-60935.
[169] "Odievre v. France, Application no. 42326/98 Judgment of 13 February 2003", Para 44, HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-60935.
[170] Joint Dissenting Opinion of judges Wildhaber, et al, in case "Odievre v. France, Application no. 42326/98 Judgment of 13 February 2003", Para 44, HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-60935.

DNA test after the death respectively. National courts in Switzerland refused to perform a DNA test grounding on the fact that the right to know one's origin is directly linked to the right to be raised by parents. Therefore, considering the fact that the applicant was 67 years old, he had already developed as an identity and did not have the need to be aware of genetic ties. The Court's opinion was that an individual's interest in discovering his parentage does not disappear with age. In fact, it can be even more crucial for a person to know this information when he or she is adult. Moreover, "the applicant has proven his true interest in ascertaining his father's identity, since he has tried throughout his life to obtain conclusive information on the subject. Such conduct implies mental and psychological suffering, even if this has not been medically confirmed".[171] Taking into account mentioned above, the Court agreed with the position of the applicant and confirmed the violation of the Art. 8 since "the preservation of legal certainty cannot suffice in itself as a ground for depriving the applicant of the right to ascertain his parentage".[172]

During this proceedings discussions criticizing Belgian authorities emerged and Jäggi's lawyer, Bruno Mégevand commented the case stating that the law has to determine that it is an individual's fundamental right to know who their father or mother is.[173]

The issues of establishing the paternity was raised in another case *Backlund v. Finland*. The applicant was deprived of the possibility "to determine his legal relationship with the person he claimed was his father, through the confirmation of the biological truth."[174] Again, the Court referred to Jaggi's judgment and confirmed that the right to know one's parents, in this case establishing parental ties between the applicant and his biological father, falls within the scope of Art.8.[175]

The situation, where the question of balancing interests arose, was in the case of *Godelli v. Italy*. The Court, yet again, clearly stipulated that the right to an identity, which includes the right to know one's parentage, is an integral part of the notion of private life.[176] The applicant claimed the violation of Art. 8 based on the fact that the State unlawfully deprived her from the possibility to search for her genetic roots and the legislature had given preference to the mother's interests without

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[171] "Jaggi v. Switzerland, Application no. 58757/00, judgment of 13 October 2006", Para 40, HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-76412.

[172] "Jaggi v. Switzerland, Application no. 58757/00, judgment of 13 October 2006", Para 43, HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-76412.

[173] "Swiss wins right to identify biological father", *swissinfo.ch*, July 18,2006, https://www.swissinfo.ch/eng/swiss-wins-right-to-identify-biological-father/1013882.

[174] "Backlund v. Finland, application no. 36498/05, judgment of 6 July 2010", Para 36, HUDOC, accessed 25 April 2020, http://hudoc.echr.coe.int/eng?i=001-99784.

[175] "Backlund v. Finland, application no. 36498/05, judgment of 6 July 2010", Para 37, HUDOC, accessed 25 April 2020, http://hudoc.echr.coe.int/eng?i=001-99784.

[176] Godelli v. Italy, Application no. 33783/09, judgment of 25 September 2012, HUDOC, accessed 29 January 2020, http://hudoc.echr.coe.int/eng?i=001-113460.

any possibilities to waive it. As a newborn the applicant was abandoned by her mother without giving consent to tell her name. During all childhood the applicant was trying to obtain the information about her origins, however all the time these attempts were blocked by the State.[177]Such cases must be examined very precisely when determining the prevailing interests.[178] Very important statement concerned the age of the interested person. The Court noted that even if the applicant was 69 years old and had already been able to develop her personality even in the absence of certainty as to the identity of her birth mother, her interest in discovering his or her parentage does not disappear with age. We can observe similar reasoning in *Jaggi v. Switzerland*. Despite the fact that the birth mother has decided to remain anonymous, "Italian law does not allow a child who was not formally recognized at birth and was subsequently adopted to request either access to non-identifying information concerning his or her origins or the disclosure of the mother's identity"[179]. Accordingly, the Court considers that the Italian authorities failed to strike a balance and achieve proportionality between the interests at stake and thus overstepped the margin of appreciation which it must be afforded.[180]

As we can see the Court sets different approaches in finding balance depending on the circumstances of the case. The judge Andras Sajo reflects the decision Godelli v. Italy as follows:

> In situations where the Convention rights of two parties come into conflict, the role of the Court is to satisfy itself that a proper balance has been struck in the case. This means that an appropriate margin of appreciation must be afforded to the domestic authorities to carry out the balancing exercise; the role of the Court is supervisory. Where the balancing exercise has been undertaken by the national authorities in conformity with the criteria laid down in the Court's case-law, the Court would require strong reasons to substitute its view for that of the domestic courts.[181]

Based on these rulings, we can conclude that the Court do not take into account any age limitations for the persons seeking for the truth. The degree of its importance cannot be measured by the years, that have passed. The emotional distress has an impact not only on a child and the need to find the genetic connection does not disappear with the reaching certain life time period.

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[177] Godelli v. Italy, Application no. 33783/09, judgment of 25 September 2012, HUDOC, accessed 29 January 2020, http://hudoc.echr.coe.int/eng?i=001-113460.

[178] Godelli v. Italy, Application no. 33783/09, judgment of 25 September 2012, Para 52, HUDOC, accessed 29 January 2020, http://hudoc.echr.coe.int/eng?i=001-113460.

[179] Godelli v. Italy, Application no. 33783/09, judgment of 25 September 2012, Para 58, HUDOC, accessed 29 January 2020, http://hudoc.echr.coe.int/eng?i=001-113460.

[180] Godelli v. Italy, Application no. 33783/09, judgment of 25 September 2012, Para 58, HUDOC, accessed 29 January 2020, http://hudoc.echr.coe.int/eng?i=001-113460.

[181] Dissenting Opinion of judge Sajo in case Godelli v. Italy, Application no. 33783/09, judgment of 25 September 2012, HUDOC, accessed 29 January 2020, http://hudoc.echr.coe.int/eng?i=001-113460.

In many of the discussed cases, the Court has to deal with the balancing the right of all involved parties. In *Mandet v. France* the paramount importance of child's interest to know the truth about genetic origins was emphasized once more. Even if biological father himself requested not to reveal information about true father to the child, the Court dismissed this request and stated that the child's right to know the truth should prevail.[182] It was stressed on the concept of 'child best interest' which local authorities were following by recognizing the fact that the interest of the child lay primarily in knowing the truth about his origins. These decisions "did not amount to unduly favoring the biological father's interests over those of the child, but in holding that the interests of the child and of the biological father partly overlapped".[183]

Very interesting issues concerns the correlation of the right to know genetic origins towards the parent who wants to search for his biological offspring. From the case when applicants tried to challenge the paternity, it could be observed that the Court gives higher priority to the child's best interest. In the case of *Kautzor v. Germany*, the applicant stated that he was a biological father of his ex-wife's daughter (who was acknowledged by a new partner of the ex-wife). Then, local authorities refused him in claims for paternity. The Court has found that states are obliged to consider whether establishing a relationship with a biological father is in the best interests of the child, for example by granting the right of contact with the child.[184]

Quite similar circumstances were showed in *Ahren v. Germany* judgment. It was concluded that "the applicant's interest to establish a paternity and have it legally recognized failed to prevail over the existing family relationship between the child and her current legal father, who provided parental care on a daily basis".[185]

In the case *Krušković v. Croatia*, the applicant claimed violation of Art. 8 due to the fact the authorities made changes in the birth certificate of his son and later on he was deprived from the possibility to establish the paternity. The matter was that Mr Krušković was legally incapable because of the mental disorder and the authorities made a conclusion that he cannot be recognized as a father in legal sense. The Court analyzed the case from the perspective of maintain the fair balance between the father's right to establish a paternity and duties of the State concerning the individual deprived of

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[182] "Mandet v. France, Application no. 30955/12, judgment of 14 January 2016", HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-160101.

[183] "Mandet v. France, Application no. 30955/12, judgment of 14 January 2016", HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-160101.

[184] "Kautzor v. Germany, Application no. 23338/09, judgment of 22 March 2012", HUDOC, accessed 1 February 2020, http://hudoc.echr.coe.int/eng?i=001-109809.

[185] "Ahrens v. Germany, Application no. 45071/09, judgment of 22 March 2012", Para 74, HUDOC, accessed 1 February 2020, http://hudoc.echr.coe.int/eng?i=001-109815.

legal capacity and their possibility to take legal actions. Having in mind that persons have a vital interest in establishing the biological truth, the Court concluded that the applicant's right to private life was violated.[186] Hence, even when the issues on establishing paternity of legally incapable individuals, the State cannot be a barrier for this actions as will cause impossibility both for offspring and parents to find out the truth.

The issue of seeking the biological origins was commented by the Court multiple times even if it was not a direct question of Art.8 violation in this respect. For instance, in cases *Phinikaridou v. Cyprus* and *Gronmark v. Finland* the Court criticized national courts, which put the general interest and rights of the presumed father and his family in greater weight than the applicant's right to find out origins.[187]

The opposite approach the Court took in the case *Chavdarov v. Bulgaria*, where no violation was found because of the impossibility for biological father to establish paternity.[188] Or in the case *Klocek v. Poland*, where the State "has failed to discharge its positive obligation to secure him effective respect for his private and family life, in particular by not providing him with the legal means for challenging his paternity, despite scientific progress and the existence of new methods of determining paternity".[189] In *Darmon v. Poland*, the fact that State dismissed the applicant's proceedings of denial the paternity, did not constitute any violations of Art. 8. as the failure to establish biological truth took place because of the daughter's personal wish but not because of State's actions.[190]

Furthermore, in certain cases the Court can even criticize the actions of authorities, which did not provide a mechanism for 'reunion' of child with biological parents even if the authorities considered that such reconnection could be harmful the child. This issue arose in the case with difficult circumstances *Clemeno v. Italy*, where the applicant was removed from her biological parents because of the suspected rape and sexual abuse by some members of her family. However, after reaching the age of majority she took a decision to find biological relatives and return to them. The Court

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[186] "Krušković v. Croatia, Application no. 46185/08, judgment of 21 June 2011", HUDOC, accessed 1 February 2020, http://hudoc.echr.coe.int/eng?i=001-105197.

[187] "Phinikaridou v. Cyprus, Application no. 23890/02, judgment of 20 December 2007", HUDOC, accessed 16 March 2020, http://hudoc.echr.coe.int/eng?i=001-84106; "Gronmark v. Finland, no. 17038/04, judgment of 6 July 2010", HUDOC, accessed 16 March 2020, http://hudoc.echr.coe.int/eng?i=001-105630.

[188] "Chavdarov v. Bulgaria, Application no. 3465/03, judgment of 21 December 2010", HUDOC, accessed 23 April 2020, http://hudoc.echr.coe.int/eng?i=001-102338.

[189] "Klocek v. Poland, Application no. 20674/07, judgment of 27 April 2010", Wolters Kluwer, accessed 23 April 2020, https://sip.lex.pl/orzeczenia-i-pisma-urzedowe/orzeczenia-sadow/20674-07-klocek-v-polska-decyzja-europejskiego-520672238.

[190] "Darmon v. Poland, Application no. 7802/05, judgment of 17 November 2009", ECHR Case Law, accessed 23 April 2020, http://echr.ketse.com/doc/7802.05-en-20091117/view/.

concluded that the authorities failed to safeguard the child's interests by not allowing the applicant to reunite with her family. It was noted that "future relations between parent and child should not be determined by the mere lapse of time and that there was at least a recommendatory obligation on signatory states to create the proper conditions to enable estranged family members to effectively communicate with each other". [191]

Radically opposite approach concerning the information about birth parents was taken by the Court in one of the last year's decisions *Leila Kahn v. Turkey*. It was concluded that impossibility to change biological parent's data in the birth certificate constitute the breach of the Convention. The Court stated that, due to the wish of adoptive parents, the name of biological parents in the identifying documents could be challenged. The applicant, Leila Kahn, grounded her claim on the fact that referrals to biological parents can lead to confusion and seriously affect her child in negative way. Taking into account the child's psychological health, she initiated changes to the birth documents, particularly in the 'mother' and 'father' column. Finally, the applicant stated that she would not want the child to doubt that she was not her biological mother. The court supported this position and therefore confirmed the violation of the right to respect the family life.[192] Thus, such changes in birth certificate will substantially minimize the future chances to become familiar with the actual circumstances of child's birth and information about biological parents.

We can see that that the matter of the disclosure of the information concerning genetic origins is decided on a case-by-case basis, taking into account all circumstances of the situation brought to the Court. There are no objections to the importance of the right to know for the person without any references to the age and the actual situation of the individuals. Also, the information regarding a person's origin has is highly-sensitive part of the private life and they conclude a vital interest for an individual. It is reasonable to consider that both youngster and an adult person have the same interest and necessity to finding 'genetic roots' and the extent of the mental harm which the one has suffered is hard to calculate. However, the Strasburg jurisprudence sets the clear position that the child's best interest should prevail, and sometimes it could be considered that non-disclosure of the information could be better for the child. And from this perspective State has a role of a 'guardian' of the best interests, which can be done either by providing the access about biological parents either by

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[191] "Clemeno v. Italy, Application no. 19537/03), judgment of 21 October 2008", HUDOC, accessed 25 March 2020, https://is.gd/UwG1xv quoted in 29. A. Diver, A Law of Blood-ties - The 'Right' to Access Genetic Ancestry (Switzerland: Springer International Publishing, 2014), 264.

[192] "Leila Kahn v. Turkey, Application no. 43140/08, judgment of 18 June 2019", HUDOC, accessed 26 January 2020, http://hudoc.echr.coe.int/eng?i=001-194200.

prevention from such ‘reunions’ with the original families when in reality this fact can be harmful to the person or conversely by providing assistance in establishing the contact with the child’s birth parents.

# 3. PROBLEMATIC ISSUES CONCERNING THE RIGHT TO KNOW ONE'S GENETIC ORIGIN.

## 3.1. Problem of donor anonymity.

Anonymity is a very important part of each individual's private life and it makes sense that every person, while relying on the anonymity clause, has certain reasonable expectations. The sphere of ART is not an exception, where the donor's anonymity is one of the most disputable issues in the light of the latest trends towards openness of genetic information.

As we have already discussed, one of the first country who prohibited donor anonymity was Sweden in 1985. Later on, the trend of abolishing it among other European countries came up, most actively in the beginning of 2000 years.[193] Nevertheless, it is necessary to explore the essence of anonymity in ART deeper, and main concerns around it, trying to find answers on the questions: why it had been applied and why some selected countries still prefer to maintain it.

From the very beginning of donations, the idea of maintaining privacy in donor treatments was highly encouraged by medical institutions and explained as "a way to normalize the conception by hiding the fact about male infertility and to protect the child from the negative impact from the side of social perception of this nontraditional form of conception".[194] Since that times anonymity in donations had been taken for granted by the society. People from different segments of the community were involved in donations. British surveys show that most frequently the donors were young males, students, whose main aim was to receive a monetary reward and they were completely satisfied with the confidentiality of this procedure.[195] In this case we can understand why the anonymity was the best option for these type of donors. Besides the completely anonymous donors, family therapist Kim Bergman distinguishes two other types: donors with revealed identity and the one, you may know. And choosing each of them has its own complications.[196]

Nowadays community is divided into supporters and opponents of anonymity with its argumentation favoring or objecting it. The core for arguments in favor is grounded on the aspects of the right to know one's genetic origin, which we have discussed in Chapter 1: medical, socio-ethical

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[193] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe,* Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 164.

[194] Susan Klock, "A Survey of Sperm Donors' Attitudes: A Much-Needed Perspective", *Fertility and Sterility* 101,1 (2014):43, https://www.fertstert.org/article/S0015-0282(13)03114-2/fulltext.

[195] Susan Klock, "A Survey of Sperm Donors' Attitudes: A Much-Needed Perspective", *Fertility and Sterility* 101,1 (2014):43, https://www.fertstert.org/article/S0015-0282(13)03114-2/fulltext.

[196] Kim Bergman, "Pros and cons of different types of donors", video source, Kids In The House, accessed 20 March 2020, https://www.kidsinthehouse.com/pregnancy/fertility/sperm-egg-or-embryo-donation/pros-and-cons-different-types-donors

aspects.[197] Essentially, people do indeed have informational needs regarding their familial, cultural and genetic ancestry which help them to understand better their personality. Considering the importance of genetics, it is understandable that the mere fact that the donor is in secret is not enough for the person to have a feeling of being a full member of society with own identity.[198] There is also a position simply stating that it is not fair to deny children the knowledge of their roots.[199] At the same time, there are 'advocates' of donor's anonymity, also providing their convincing arguments as well. They express concerns about the donors' rights to privacy, the donor's parental status, the attitude of donor's own families, a scope of the basic need of intended parents to enjoy reproductive rights and form a family without unreasonable State's intervention.[200]

We will study arguments of supporters the idea in order to form a comprehensive understanding of this problem. Justifications provided in favor of donor anonymity can be divided into several blocks. First of all, the emphasis is always put on the donor's right to privacy in the medical procedures he has been gone though, including donations. Within the European Union the donor's right to privacy is guaranteed by Art.21 of the Charter of the Fundamental Rights of European Union, Art.21 of the Oviedo Convention and the recommendations of the European Group on Ethics on genetic testing, which state that "all medical data, including genetic data, must be afforded equally high standards of quality and confidentiality at all times".[201] By entering to the agreements, donor usually have a reasonable expectations for a complete confidentiality and consequently in most cases unwilling to disclose the information concerning the treatments they had.

Another point in favor of anonymity is that it serves as an assurance of prevention of future contact with offsprings. It excludes the possibility for donor to be considered a legal father and presents the donation simply as a formal economic contract.[202] However, it is worth to mention that

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[197] 118. Vardit Ravitsky. "Knowing Where You Come From: The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness", Minnesota Journal of Law, Science & Technology 11(2), (2010):655-684.

[198] M. Kirkman, "Parents' contributions to the narrative identity of offspring of donor-assisted conception", *Social Science & Medicine*, 57,11 (2003):2231

[199] Margaret Nelson, Rosanna Hertz, Wendy Cramer, "Gamete donor anonymity and limits on numbers of offspring", *Journal of Law and the Biosciences* 29,1 (2015):3, https://www.researchgate.net/publication/283487271_Gamete_donor_anonymity_and_limits_on_numbers_of_offspring_the_views_of_three_stakeholders.

[200] Margaret Nelson, Rosanna Hertz, Wendy Cramer, "Gamete donor anonymity and limits on numbers of offspring", *Journal of Law and the Biosciences* 29,1 (2015):4, https://www.researchgate.net/publication/283487271_Gamete_donor_anonymity_and_limits_on_numbers_of_offspring_the_views_of_three_stakeholders.

[201] Christian Lenk, Nils Hoppe, Katharina Beier, Claudia Wiesemann, *Human Tissue Research: A European Perspective on the Ethical and Legal Challenges*, (Oxford: Oxford University Press, 2011), 123.

[202] Aliya Shain, "A Veil of Anonymity: Preserving Anonymous Sperm Donation While Affording Children Access to Donor-Identifying Information", *CUNY Law Review* 19, 2 (2016):318, https://academicworks.cuny.edu/clr/vol19/iss2/6.

chances that claims for the recognition of parentage will be successful are rather low. There was a case in Ireland, which lead to Irish Supreme Court where donor wanted to keep contact with his offspring and prove his parental status. Even, if the ruling stated that “the man has 'natural rights' over the son, he could not be entitled to guardianship over the boy and no legal relations could exist between them”.[203] In order to secure donors from potential legal relations with his offspring, “the law should clarify the legal relationship between donors, parents, and offspring and that donors must be assured that they have no parental rights or obligations”.[204] The concerns about potential legal consequences for donors can be removed by the provisions that they are protected from any court proceedings concerning determinations of parentage, any inheritance issues and so forth. That will help the potential donors to fell more sure while the participating in ART procedures and create a legal protection from future claims. Many states already have such clauses in the legislation, particularly Germany.[205]

While discussing the parental aspect of the right to know one’s genetic origin, we mentioned that the issue of secrecy could be a concern to non-traditional families as well, such as homosexual couples. Aliya Shain states that in case of unveiling the anonymity “a non-biological mother who adopted her partner’s donor-conceived child might feel that her role as a parent is illusory if the child is able to locate his or her biological father, despite the conscious efforts of the non-biological parent to become a mother”[206]. It shows that it is psychologically easier for such families to consider themselves as parents knowing that donor is kept in secret. Still, it will be hard to conceal the gravity of the situation for a long while as it is obvious that in such families the child could not be born in natural way and it is only a matter of time when does a donor-conceived child ask about his or her genetic parents.[207]

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[203] Ben Jones, “Sperm Donor Wants To See The Child”, Bionews, accessed 18March 2020, https://www.bionews.org.uk/page_92053.

[204] Naomi Cahn, “The New Kinship”, *Georgetown Law Journal* 100,2 (2012):416, https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2018969.

[205] Claudia Brügge, Petra Thorn, “How Germany's new Sperm Donor Registry Act is internationally progressive”, Bionews, accessed 22 February 2020, https://www.bionews.org.uk/page_96069.

[206] Aliya Shain, “A Veil of Anonymity: Preserving Anonymous Sperm Donation While Affording Children Access to Donor-Identifying Information”, *CUNY Law Review* 19, 2 (2016):318, https://academicworks.cuny.edu/clr/vol19/iss2/6.

[207] C. Murray, S. Golombok, “Going It Alone: Solo Mothers and Their Infants Conceived By Donor Insemination”, *American Journal of Orthopsychiatry* (2005):242; F. Maccallum, S. Golombok, “Children Raised in Fatherless Families from Infancy: A Follow-Up of Children of Lesbian and Single Heterosexual Mothers at Early Adolescence” *Journal of Child Psychology and Psychiatry* (2004):1407 quoted in Tabitha Freeman, Sophie Zadeh, Venessa Smith, Susan Golomboka, “Disclosure of sperm donation: a comparison between solo mother and two-parent families with identifiable donors”, *Reproductive Biomedicine Online* 35,5 (2016):592–600, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5084687/.

One more psychological concern may appear for people who used ART. Particularly, social parents can use the donor's secrecy as a 'cover-story' for their own fears and anxieties  Anonymity can help them to remove the feeling of 'shame' that they are not able to have a child and keeping the sperm donation in secret can be considered as a way to protect the perceived threat to their fertility.[208] In addition, it can make it easier for sterile couples to constitute their parental role. Anonymity was considered as a barrier from any fear of interference from the child's biological parent. Moreover, the confidential status of donor conception was regarded as a way for securing the parents' privacy: they could decide independently either to keep the fact about using ART between themselves or, on the contrary, to inform the child or the family about the details of conception.[209] The parents believe that the fact of using donor is a matter of concerns only for them and should not be shared with the child. Some of parents are afraid of a potential negative attitude towards their children from the other children. There are people who want their family to be 'al right', like the others. When the donor is anonymous, it also blocks the parents from telling their children because they will not be able to answer to their questions about the identity of the genetic parent.[210] Despite the fact that such a parental perspective could be understood from the psychological  point of view, it is very one-sided approach which do not take into account the child's real needs.

Further, anonymity supporters believe that countries, where ART is used and has legal regulation of this process, are focusing enough on health safety and other aspects of donor conceptions and thus take adequate measures to prevent possible diseases of offsprings.[211] For instance, in USA the screening of donors for diseases such as HIV and genetic anomalies is a normal  routine practice[212] or the fact that fertility providers are required to report to the special authorities responsible for disease control, which publish a yearly report about every clinic and their IVF success rates.[213] We have to

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[208] Rachel Gurevich, "Understanding Donor Arrangements", Very well Family, accessed 19 March 2020, https://www.verywellfamily.com/understanding-donor-arrangements-4176290.

[209] Laurence Brunet, Jean-Marie Kunstmann, "Gamete donation in France: the future of the anonymity doctrine", *Medicine, Health Care and Philosophy, A European Journal* 16,1 (2012):8, https://www.researchgate.net/publication/230756393_Gamete_donation_in_France_The_future_of_the_anonymity_doctrine.

[210] Krastev R, Mitev V., "The Donation of Gametes and the Anonimity of the Donors", *Acta Medica Bulgarica* 42,1 (2015):6, https://content.sciendo.com/view/journals/amb/42/1/article-p5.xml.

[211] Margaret Nelson, Rosanna Hertz, Wendy Cramer, "Gamete donor anonymity and limits on numbers of offspring", *Journal of Law and the Biosciences* 29,1 (2015):3, https://www.researchgate.net/publication/283487271_Gamete_donor_anonymity_and_limits_on_numbers_of_offspring_the_views_of_three_stakeholders.

[212] Bebe J. Anderson, "Lesbians, Gays, and People Living with HIV: Facing and Fighting Barriers to Assisted Reproduction", *Gardozo Journal of Law and  Gender*, 15, (2009):455, https://www.law.berkeley.edu/php-programs/centers/crrj/zotero/loadfile.php?entity_key=PGP924X9.

[213] Margaret Nelson, Rosanna Hertz, Wendy Cramer, "Gamete donor anonymity and limits on numbers of offspring", *Journal of Law and the Biosciences* 29,1 (2015):4,

admit, that the refereed argument is rather weak as it is impossible to apply it to the overall situation with ART. Even on the assumption that there are clinics who take this responsibility highly, it is difficult for them to provide the guarantees for absolute healthy offsprings. What is more, there is a big number of genetic diseases, which are not tested by the clinics on the routinely basis. One of the cases may arise, when the donor's disease appears only many years after conception. Moreover, a big reformations of healthcare systems should be conducted in order to enable rigorous control of all involved clinics.

Surveys have also studied the attitudes of donors concerning the status of anonymity and particularly disclosure. One study found that, although sperm donors generally support sharing non-identifying information, the majority of sperm donors still are insisting on having their identity unknown to the recipients and the child respectively.[214] When donors were asked what type of openness they would accept if anonymity was changed,

> […] the two-thirds would like to know only the number of children that were born from their sperm, approximately one-half would accept that the child could know their identity, and only a small part would accept contact from the child. This is in contrast to results of a study of donor offspring indicating that donor offspring consider the sperm donor to be their "biological father" and would like identifying information about their donor as well as to meet the donor and establish a relationship with him.[215]

It should be noted that the attitude of donor mat change during the time because of different circumstances. For instance, an anonymous donor who, after having children of his own, may want to be known but generally will not have a possibility to change the situation. There were suggestions that clinics may contact again previous donors in order to ask them whether they want to be identified and available for contact.[216]

Concerning the argument that donor's anonymity will influence the number of donations, several researches has already proved that the situation is not so negative and hopeless. The countries which were abolishing donor's anonymity had big concerns that such step will lead to the donation shortage. The results are different around the countries. Some countries faced drops in the number of donors by removing the donor anonymity, which later led to long waiting lists for patients, increased

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https://www.researchgate.net/publication/283487271_Gamete_donor_anonymity_and_limits_on_numbers_of_offspring_the_views_of_three_stakeholders.

[214] Susan Klock, "A Survey of Sperm Donors' Attitudes: A Much-Needed Perspective", *Fertility and Sterility* 101,1 (2014):44, https://www.fertstert.org/article/S0015-0282(13)03114-2/fulltext.

[215] P. Mahlstedt, K. LaBounty, and W.T. Kennedy, "The views of adult offspring of sperm donation: essential feedback for the development of ethical guidelines within the practice of assisted reproductive technology in the United States", *Fertility and Sterility* 93 (2010), https://www.fertstert.org/article/S0015-0282(08)04835-8/fulltext.

[216] Guido Pennings, "The 'double track' policy for donor anonymity", *Human Reproduction* 12,12 (1997):2841.

cross-border health care and increased import of foreign donor sperm.[217] However, in some countries the statistic shows that afterwards the donation has been increased.[218] For instance, in Sweden the percentage of donors became bigger the year after the anonymity ban. The results of national Swedish survey, published in January 2011 on the website of international Journal Human Reproduction, proved it. The article, written by S. Isaksson and other researchers, was titled ‘‘Two decades after legislation on identifiable donors in Sweden: are recipient couples ready to be open about using gamete donation?”.[219] The outcome showed the attitude of the parents towards informing the children that they were conceived, the major part stated about their intention to tell the children the truth. “They even added that they considered that to be a basic duty of ‘honesty’ as well as a duty to respect their children's ‘rights’.”[220] At the same time the decrease in the supply of donor materials in Britain was not lasting  for a long time after a ban on anonymously donated sperm from 2005.[221] Therefore, the outcomes in activity of donors differ from country to country and we consider that it is rather disputable argument in favor of anonymity. If the global social perspective on anonymity changes, it will not lead to the decrease of the number of volunteers willing to donate.

Previously we have discussed how selected states are granting the right to know about genetic origins on the legislative level. However, there are other countries, which still are protecting donor's anonymity. During studies of ECHR court practice, we noticed that France is strict when it comes to the anonymous birth. Further, France developed the known model of donor's anonymity. Since the approval its bioethics laws in 1994, this concept prevails, starting from the post war blood-bank policy, when blood donations were completely anonymous. Taking into account the success of these donations the legislators used the same approach to all other possible donations of parts of human body.[222] In autumn 2019 The French National Assembly began discussion about the initiation of the law regulating the bioethics issues. This law should stand for the abolition of anonymity of future sperm donors. However, children who was  born as a result of ART before also have the right to know

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[217] Annelies Thijssen et. al,“Motivations and attitudes of candidate sperm donors in Belgium”, *Fertility and Sterility* 108,3 (2017):544, https://www.fertstert.org/article/S0015-0282(17)30438-7/pdf.

[218] Anne-Marie Leroyer, “Why should France change its legislation relating to donor anonymity? A prospective comparative study”, accessed 16 Mach 2020, https://doi.org/10.26262/culres.v5i0.4948.

[219] S. Isaksson et al, “Two Decades After Legislation on Identifiable Donors in Sweden: Are Recipient Couples Ready to be Open About Using Gamete Donation?”, *Human Reproduction* 26,4, (2011):853.

[220] Anne-Marie Leroyer, “Why should France change its legislation relating to donor anonymity? A prospective comparative study”, accessed 16 Mach 2020, https://doi.org/10.26262/culres.v5i0.4948.

[221] Denise Grady, “Shortage of Sperm Donors in Britain Prompts Calls for Change”, *The New York Times*, November 11,2008, http://www.nytimes.com/2008/11/12/health/12sperm.html.

[222] Laurence Brunet, Jean-Marie Kunstmann, “Gamete donation in France: the future of the anonymity doctrine”, *Medicine, Health Care and Philosophy, A European Journal* 16,1 (2012):3-4, https://www.researchgate.net/publication/230756393_Gamete_donation_in_France_The_future_of_the_anonymity_doctrine.

their origin nowadays this position has been argued many times as no discussions were raised regarding their rights.[223] Those the rights of children who are already born via ART should be also taken into account while discussing a potential reformation of this issue.

Another model of anonymity is maintained by Denmark. From the 2012 it is allowed to choose between anonymous and known donors.[224] Researchers believe that "precisely because of its anonymous policy, the Danish sperm bank is one of the leaders in Europe".[225] At the same time it causes another problem. As due to the EU legislation, particularly Directive 2004/23/EC which establishes the free movement of cells and tissues, every licensed sperm bank can supply donor sperm to anybody in all member states country. [226] Furthermore, the level of disclosure of donor identity can have an impact on the price of the treatment: the more information is available about the donor, the more costly the procedure is for the future parent.[227]

Considering all mentioned above, the main problems concerning donor's anonymity can be explained in various aspects:

- there is an opinion that countries, which provide people with a possibility to donate anonymously, seem more attractive to potential donors. In case of abolishing donor secrecy, the number of volunteers to donate can change as mostly the reason why they agree to donate is complete anonymity. However, as explained above, several researches conducted in Sweden and UK show the opposite and even states that very often people providing donor material have altruistic intentions;[228]
- problems for fertility clinics: they cannot provide their clients (in this case donors) with a guarantee of non-disclosure of their identity. Practitioners says that is significantly easier to recruit a potential sperm donor if you tell him that he can be anonymous.[229] Still referring to the clause above, in certain cases that is not the most important conviction for the donor;

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[223] "Assemblée national XVe legislature Seconde session extraordinaire de 2018-2019 Compte rendu integral", French National Assembly, Accessed 24 March 2020, http://www.assemblee-nationale.fr/15/cri/2018-2019-extra2/20192010.asp

[224] Janne Rothmar Herrman, "Anonymity And Openness In Donor Conception: The New Danish Model", *European Journal of Health Law* 20, (2013):505.

[225] Janne Rothmar Herrman, "Anonymity And Openness In Donor Conception: The New Danish Model", *European Journal of Health Law* 20, (2013):505.

[226] Janne Rothmar Herrman, "Anonymity And Openness In Donor Conception: The New Danish Model", *European Journal of Health Law* 20, (2013):505.

[227] Elodie Decorte, "Donor Conception: From Anonymity to Openness, Plurality and Diversity of Family Relations in Europe" in Plurality and Diversity of Family Relations in Europe, Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 170-171.

[228] Denise Grady, "Shortage of Sperm Donors in Britain Prompts Calls for Change", *The New York Times*, November 11,2008, http://www.nytimes.com/2008/11/12/health/12sperm.html.

[229] Meghana Keshavan, "There's no such thing as anonymity': With consumer DNA tests, sperm banks reconsider long-held promises to donors", *STAT News*, September 11,2019, https://www.statnews.com/2019/09/11/consumer-dna-tests-sperm-donor-anonymity/.

- in some cases, donors are not supporting the idea of disclosing information and prefer to remain anonymous. Those, the child can suffer rejection from the donor and potentially face psychological harm, which may be caused by informing the child about donor-parent and which will be much stronger than benefit from it;[230]
- when donor anonymity is applied it is much harder to have control over the number of offsprings from one donor. And taking into account that generally there are no limits set on the legislative level, it will be impossible to handle the magnitude of same-donor procedures.

Still, it is important to mention, that the matter of anonymity cannot be evaluated only basing on the arguments of donors. All fears and concerns around the ban on anonymity mainly are touching only personal interests of donors, social parents, while not enough attention to the child's best interest is given.

## 3.2. Conflict of interests of genetic/birth parents, social parents and offspring: problems and challenges around it.

It is necessary to weight rights of all involved parties in order to realize all ethical and legal issues concerning the right to know genetic origins. Only by determining who will be harmed and who will benefit to which extent will help to understand which solution can be more reasonable and fair.[231]

It is argued that the interests of a donor-conceived child are "even owed particular consideration because the child is the one party who was not involved in the decision to use a donor, but who still is the most affected by the consequences".[232] However, it is worth to stress that in the following situation naturally conceived children with misattributed paternity are in the same position and are also harmed and frustrated to the same extent as donor-conceived children who lack information about their genetic origin.[233] It is considered that this lack of information "jeopardizes child's capacity to develop an understanding of his or her identity and to make informed decisions regarding reproductive, medical, and family-related matters".[234]

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[230] De Melo Martin, "The ethics of anonymous gamete donation: Is there a right to know one's genetic origins?", *Hastings Center Report*, 44,2 (2014):33.

[231] Rebecca Johns, "Abolishing Anonymity: A Rights-Based Approach to Evaluating Anonymous Sperm Donation", *UCLA Women's Law Journal* 20, 2 (2013):116.

[232] K. R. Daniels, P. Thorn, "Sharing information with donor insemination offspring: A child-conception versus a family-building approach", *Human Reproduction* 16, 9 (2001):1793.

[233] An Ravelingien, Guido Pennings, 'The Right to Know Your Genetic Parents: From Open-Identity Gamete Donation to Routine Paternity Testing", *The American Journal of Bioethics*, 13,5 (2013):34.

[234] An Ravelingien, Guido Pennings, 'The Right to Know Your Genetic Parents: From Open-Identity Gamete Donation to Routine Paternity Testing", *The American Journal of Bioethics*, 13,5 (2013):37.

We support the opinion that whether children are adopted, conceived by anonymous donor, or do not know the birth parents by other reason, they should have equal access to information that is deemed crucial for a full estimation of their health risks and a true picture of who they are and where they come from.[235]

In Chapter 1 we addressed the importance of disclosure of this information for adoptees as it had a significant impact on identity formation in the society. The arguments in favor of disclosure to donor-conceived individuals often refer to the analogy with adoptees. Adoption and donor-assisted conception are different in the fact that adoption involves the creation of a family around the already existing individual while donor conception is a form of human reproduction where one parent is biologically related to the child and the child's birth is highly desired.[236] What is more, in adoption proceedings, the State is usually involved because in most countries adoption is a "state-created and state-controlled procedure". Consequently, the State take part in the adoption process and is responsible for regulating identifying information in adoption cases. In ART the situation is the opposite, the medical professionals and parents themselves rather than the State are generally engaged in the procedure of anonymous artificial insemination.[237]

Considering mentioned above, we can see that detailed analysis is essential to understand how to maintain the balance between the rights of all involved parties and find a clue whether it is possible to adapt the interests of parents and donors to the latest trends towards openness?

From the human rights approach, the following conflict of interests arise as all involved parties have equal rights to respect private and family life granted by Art. 8 of the Convention.[238] Both genetic and social parents have a right to respect private life without any interference. At the same time, offspring has the same right and cannot be deprived of it simply because someone had already decided for them.

The problem of balancing rights of biological parents, social parents and offspring has been subject to many discussions. The Committee on Social Affairs, Health and Sustainable Development of the Council of Europe has developed a set of recommendations for states in order to improve the protection of the rights of all the parties concerned (the parents, the donors and the children). It put a

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[235] An Ravelingien, Guido Pennings, 'The Right to Know Your Genetic Parents: From Open-Identity Gamete Donation to Routine Paternity Testing", *The American Journal of Bioethics*, 13,5 (2013):34.

[236] Erica Haimes, "Secrecy': What Can Artificial Reproduction Learn From Adoption?", *International Journal of Law, Policy and the Family* 2,1 (1988):46, 47.

[237] Erica Haimes, "Secrecy': What Can Artificial Reproduction Learn From Adoption?", *International Journal of Law, Policy and the Family* 2,1 (1988):46.

[238] "The European Convention on Human Rights", European Court of Human Rights, Accessed 15 January 2020, https://www.echr.coe.int/Pages/home.aspx?p=basictexts&c.

focus on the rights of the donor-conceived person, who, in the Committee opinion, “is in the most vulnerable position and for whom the stakes appear to be higher”.[239] “Despite the fact that parents are granted the rights regarding privacy, family right, reproductive rights, are nonetheless assumed to be directly responsible for their children’s welfare. Indeed, the best interest of the child is the guiding principle in present-day family law”[240] and has to be the one of main concerns for parents as well.

We have raised the problem which may be faced by homosexual couple due to the fact of knowing the donor. In this case the Committee suggested

> […] not to abolish the anonymity requirement completely, but simply to waive it so that the parents cannot know the identity of the donor at the moment of insemination and vice versa, but the donor-conceived person can later have access to certain information. It is therefore more accurate to talk in terms of access to information rather than abolition of the principle of the anonymity of gamete donation. However, there would seem to be certain practical, as well as ethical, obstacles to such a waiver of the anonymity requirement.[241]

As an option for balancing the rights of donors and social parents the policy of choosing between two types of donors was introduced. In literature can be found as ‘double track’ policy, which provides a possibility to choose between anonymous donors and the ones with open identity. [242] This policy could be taken into consideration as it provides the parties of the conception with a possibility to decide for themselves. The donor choses whether he wants to be identified and the future parent chooses the group in which the first party (donor) has placed himself.[243] Nevertheless, we argue that such policy leaves aside no less important actors - offsprings, who still are without any opportunity to trace the origins if their social parents decide not to share with them the mere fact about donation. Objectors of ‘double track’ policy refer to a potential discrimination of offsprings which may appear, because they will be divided into two groups: those, who may have an access to information about their genetic parents and those who may not. Therefore, the parents can deprive the child of the right

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[239] Introductory memorandum declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 28 June 2018 in Strasbourg
*Anonymous donation of sperm and oocytes: balancing the rights of parents, donors and children*

[240] E. Chestney, “The right to know one’s genetic origin: Can, should, or must a state that extends this right to adoptees extend an analogous right to children conceived with donor gametes?”, *Texas Law Review,* 80,2 (2001):365–391.

[241] “Introductory memorandum declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 28 June 2018 in Strasbourg: Anonymous donation of sperm and oocytes: balancing the rights of parents, donors and children”, Counsil of Europe, Accessed 22 March 2020, http://www.assembly.coe.int/LifeRay/SOC/Pdf/DocsAndDecs/2018/AS-SOC-2018-22-EN.pdf.

[242] Kimberly Leighton, “To Criticize the Right to Know We Must Question the Value of Genetic Relatedness”, *The American Journal of Bioethics* 13,55 (2013):54-56, https://www.academia.edu/5051616/To_Criticize_the_Right_to_Know_We_Must_Question_the_Value_of_Genetic_Relatedness.

[243] Guido Pennings, “The ‘double track’ policy for donor anonymity”, *Human Reproduction* 12,12 (1997):2839.

to know simply by not telling them that relevant information. [244] That means that 'double track' system offers no solution to the problem of the children who wish to know the identity of their genetic parents but rather propose the options for parents and donors.

Parents' reasons for not informing their children differ on the case-by-case basis. Some intended parents indicate that they were uncertain, very often concentrate only on their own role as parents and their desire to act in their children's best interests.[245] In Chapter 1 we have discussed several studies of the perspective parent's attitude towards the role of donors in their life. They showed different impressions: from the one side, they felt gratitude toward the donor for the possibility to go through parental status and the belief that the donor is a kind person; on the other hand, they expressed the desire to never meet the donor, the fear that the child might treat the donor as the 'real' parent. Also they think of donors as reminders of their fertility problems and the possible feeling of 'shame' connected with it.[246] Other studies found that the reason why parents were against disclosure or unsure about telling the truth could be also attitude of family members to the child. They wanted to keep information in secret simply to protect their children from the feeling that they are not a part of the family. This harmful truth may at times damage relationship, and parents are often afraid of the consequences of such knowledge taking into account interests of the family. The desire to know the truth may become less preferable for the sake of family stability and security in the child's wellbeing. And discovering the truth can harm family members and disrupt these relationships.[247] That is why it is common that parents are indecisive when it comes to the moment of disclosure.

Banning donor anonymity and pushing psychological complexities of donor conception can also lead to the great escalation undesirable social process 'reproductive tourism'.[248] As normally people cannot be deprived of their right to use modern reproductive technologies in order to exercise the right to have a family. So in the pursue of exercising their rights to family parents are choosing alternative options. 'Reproductive tourism' is defined as "a modern phenomenon which is used by people crossing country borders in order to access reproductive technologies, which is followed by

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[244] Guido Pennings, "The 'double track' policy for donor anonymity", *Human Reproduction* 12,12 (1997):2840

[245] Victoria M. Grace, "The Donor, the Father, and the Imaginary Constitution of the Family: Parents' Constructions in the Case of Donor Insemination", *Social Science & Medicine* 66, 2 (2008):302.

[246] Victoria M. Grace, "The Donor, the Father, and the Imaginary Constitution of the Family: Parents' Constructions in the Case of Donor Insemination", *Social Science & Medicine* 66, 2 (2008):302.

[247] Brigitte Clark, "A Balancing Act? The rights of Donor-Conceived Children to Know Their Origins", Georgia Journal of International and Comparative Law 40,3 (2012):641, https://digitalcommons.law.uga.edu/cgi/viewcontent.cgi?referer=&httpsredir=1&article=1001&context=gjicl.

[248] Brigitte Clark, "A Balancing Act? The rights of Donor-Conceived Children to Know Their Origins", Georgia Journal of International and Comparative Law 40,3 (2012):659, https://digitalcommons.law.uga.edu/cgi/viewcontent.cgi?referer=&httpsredir=1&article=1001&context=gjicl.

various legal, ethical, and risk-management challenges"[249]. The exact statistic of such 'tourism' is difficult to calculate, but approximate numbers are scored in thousands in Europe alone and in hundreds of thousands in Asia.[250] Generally, the need to travel for reproductive services is shaped by a combination of legal restrictions forcing people to go out of their home countries and attractive services drawing patients to foreign countries to access those services.[251]

The reason why we cover this issue within the topic of the present thesis is that people in pursuit of their wish to have a child are avoiding legal bans existing in their countries. We will focus our attention more on the influence of the 'reproductive tourism' on the right to know one's genetic origin. It is known that there is no clear and integrated standard for States concerning enforcing and guaranteeing the right to know the genetic origin. Even if generally a global towards openness can be noticed, each country deals with this issue by its own means and to its own discretion. We know the examples of full disclosure of donor's identity after reaching a required age of the offspring (Sweden, Netherlands) and at the same time jurisdictions with anonymity still exist.[252] The interest of social parents lays in possibility to have the same reproductive rights as other members of the society. Thus, they will be interested in keeping anonymity of donor as it allows them to realize their right to procreate,[253] to have a family without any interferences. At the same time the interest of the child will play important role as for conscious parents it is heartbreaking to watch how the child undergoes any kind of emotional distress. In case of anonymous donation, the child will try to search for something which is nearly impossible to find.[254] And that will be harmful for the whole family.

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[249] Raywat Deonandan, "Recent trends in reproductive tourism and international surrogacy: ethical considerations and challenges for policy", *Risk Management and Healthcare Policy* 8 (2015):111, https://www.researchgate.net/publication/281066804_Recent_trends_in_reproductive_tourism_and_international_surrogacy_Ethical_considerations_and_challenges_for_policy.

[250] Raywat Deonandan, "Recent trends in reproductive tourism and international surrogacy: ethical considerations and challenges for policy", *Risk Management and Healthcare Policy* 8 (2015):111, https://www.researchgate.net/publication/281066804_Recent_trends_in_reproductive_tourism_and_international_surrogacy_Ethical_considerations_and_challenges_for_policy.

[251] Nygren K, Adamson D, Zegers-Hochschild F, de Mouzon J., "Cross-border fertility care – International Committee Monitoring Assisted Reproductive Technologies global survey: 2006 data and estimates", *Fertility Sterility* 94 (2010), https://www.sciencedirect.com/science/article/abs/pii/S0015028209042988.

[252] 56. Elodie Decorte, "Donor Conception: From Anonymity to Openness, Plurality and Diversity of Family Relations in Europe" in *Plurality and Diversity of Family Relations in Europe*, Katharina Boele-Woelki and Dieter Martiny (eds.), Intersentia, 2019.

[253] Rebecca Johns, "Abolishing Anonymity: A Rights-Based Approach to Evaluating Anonymous Sperm Donation", UCLA Woman's Journal 20,2 (2013):121.

[254] Rebecca Johns, "Abolishing Anonymity: A Rights-Based Approach to Evaluating Anonymous Sperm Donation", UCLA Woman's Journal 20,2 (2013):121.

We consider reproductive tourism as a big barrier for the right to know one's genetic origin, which creates difficulties on the way for securing this right. The main complications around it could be formulated as follows:

- even if countries implement its legislations to the level of absolute openness of genetic information, preclude anonymous donations in ART, provide an easy access to all registers and databases, all these changes could be nullified by a just possibility to experience ART in other countries, which do not set any restrictions;
- the individual who was conceived in the country with anonymous donations afterwards will be born in the parent's home country (where the right to know the truth about birth is granted) will appear in confused situation, can even feel discrimination and most likely will never be able to find that truthful information. As an example, we can provide Sweden. The unconditional legal right applies only to donor offspring conceived under the *Genetic Integrity Act*. That means that private arrangements (inseminations which are not performed in hospitals that have been authorized to perform such procedures by the National Board of Health and Welfare) or following treatment procedures carried out abroad have no right to information about the donor under the mentioned Act.[255]

Therefore, reproductive tourism is a way more dangerous social phenomenon than it seems to be from the first sight. Together with avoidance of national restrictions regarding anonymity, perspective parents are 'running away' from their responsibility to take into consideration the child's interests. The possibility to enjoy the right to know the truth about origins is put in high risk if prospective parents are allowed to use ART abroad. That is why the unified and integrated approach is needed in the regulation of these matters. Particularly, creating common standards in the regulations of conducting ART procedures with a clear indication of donor status, establish a mechanism of tracking of genetic origins on the international level, enable intercountry cooperation of fertility centers, clinics, and other involved authorities.

Considering all mentioned above, we have to highlight the necessity to choose the correct approach in balancing the rights of genetic/birth parents, social parents and children. There are no doubts, the right to know the genetic origin should be provided for everyone without any preferences whether the individual was born as a result of ART, or was naturally born and later adopted. Hence,

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[255] Pikramenou Nikoletta, "Reproductive Tourism in Europe: Legal and Ethical Issues" (master thesis, Uppsala University, 2014):35, https://www.constitutionalism.gr/wp-content/uploads/2014/08/2014_Pikramenou-Nicole_Reproductive-tourism.pdf.

the states are responsible for providing this possibility while minimizing potential harm to other involved parties. For instance:

- promoting the idea of openness in the society (educating the community about the importance of disclosure; cooperation with psychologists, family counselors; establishing associations for the support of families; organize consultations for prospective parents and donors);
- implementation of the 'track of origins' policies and assurance mechanisms that person has access to the information about genetic origins (creation databases; providing unimpeded access to them);
- securing rights of all involved parents (exclude risks of legal claims from the offsprings to donors; impossibility for donors to obtain a status of the legal parent);
- establishing common integrated standards as part of international cooperation.

### 3.3. The problem of ensuring the disclosure of information to the offspring and possible solutions.

It is clear that the right to know one's genetic origin is crucially important for the formation of identity and this position is supported by the ECHR. Nevertheless, the challenges which both parents and children may face during the disclosure of the truth still are big and lead to the creation of many other complications.

Even if we presume that the donor's anonymity is banned, the procedure of conception is completely open, there is a lack of certainty in which way the disclosure should be done to be beneficial for the child. Similarly, it is hard to be completely sure that parents will share this information with the child. Furthermore, yet again, the risk appears that the child will not even make an attempt to find the genetic relatedness simply because he or she is not aware of the fact itself. In bioethical researches it is argued that the right to know involves the right to be told.[256]

Actually, there is no real sense of granting the right to know about something, which the person is not aware of at all. As an option to be sure that parents will tell the child truth about genetic origin is to set an obligation. Several researches proposed different models of mandatory disclosure

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[256] An Ravelingien, Guido Pennings, 'The Right to Know Your Genetic Parents: From Open-Identity Gamete Donation to Routine Paternity Testing", *The American Journal of Bioethics*, 13,5 (2013):35.

mechanisms, which included recording the fact of donor conception on birth certificates, formal linking of such information to the birth certificate registries.[257]

It may seem that it is a good way to deal with the problem of parent's unwillingness to disclose this information to children is an establishment of a special note on the birth certificates of all children who was born as a result of ART. Such a variant was proposed in United Kingdom based on the fact that generally parents have no obligations to inform their children of the nature of their birth (amendments to UK's Human Fertilization and Embryology Bill).[258] Particularly, indicating specific symbols on a certificates of donor-conceived individuals. Another alternative within the discussion precluded issuing 2 types of birth certificates: 'Full Certificates', which indicate both genetic and legal parents and 'Short Certificates' which will be undistinguishable from the traditional ones; or establishing 2 stages of child registration and obtaining 'Birth Certificate' and 'Parentage Certificate'. These certificates were supposed to "partially satisfy privacy concerns by the inability of a third party to access the original birth certificate which indicates that there may be something unusual about the circumstances of the individual's birth registration".[259]

A similar model of a special mark in birth certificates was discussed in Ireland. While the Irish Fertility Counsellors Association (hereinafter – the IFC) generally supported the idea of the right to know the genetic origin, still they had certain doubts about moral aspect of the indication the fact about donor concession in birth certificates. The IFC stated the operating with this information in public offices by unprepared and untrained staff could be very concerning. Even a tiny mistake could lead to a serious breach of data protection and confidentiality, and would likely raise a number of questions from prospective employers, heads of educational establishments and intended parents.[260]

On the one hand, special birth notes will make it more difficult for parents to hide the crucially important information from the child. On the other hand, this can cause additional psychological burden both for the parent and child as individuals in society. The reality is that birth certificates are documents, which are required to be filed during many events and actions in our everyday life, what means that many other people will be aware of the fact of birth through conception.[261] We believe that

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[257] An Ravelingien, Guido Pennings, 'The Right to Know Your Genetic Parents: From Open-Identity Gamete Donation to Routine Paternity Testing", *The American Journal of Bioethics*, 13,5 (2013):34

[258] Antony Starza-Allen, "Lords propose inclusion of donor-conception information on birth certificates", Bionews, accessed 16 March 2020, https://www.bionews.org.uk/page_90560.

[259] E. Blyth et al, "The Role of Birth Certificates in Relation to Access to Biographical and Genetic History in Donor Conception'", *International Journal of Children's Rights* 17 (2009):220-223.

[260] Jeny Cloherty, "Donor-conceived children and the law", *The Irish Times* July 23, 2018, accessed 25 March 2020, https://www.irishtimes.com/opinion/letters/donor-conceived-children-and-the-law-1.3572794.

[261] Antony Starza-Allen, "Lords propose inclusion of donor-conception information on birth certificates", Bionews, accessed 16 March 2020, https://www.bionews.org.uk/page_90560.

in this case too much pressure would be made on parents and they will be literally forced to inform the child about the existence of donor without proper consideration of the right moment and way in which they have to tell this information. Their sole concern will be to inform the child as soon as possible otherwise they are not following the obligation and risk to face sanctions. Although we know how sensitive the issue in question is and that it can directly contradict with child's best interest.

There is another idea how to ensure the disclosure by social parents. Due to impetuous development of genetic science and all technologies in this field, it was proposed to establish the mandatory routinely parental testing. "While this suggestion may sound impractical and vague, the meaning of it was to put forward a realistic and feasible scenario that could theoretically ensure universal respect for the right to know: one in which DNA paternity testing is routinely performed on the newborns of heterosexual couples. DNA paternity tests are a reliable and easy way to discover the genetic relationship between a man and child."[262] Besides we consider such method as very 'sharp' and drastic towards parents and the respect to their private life. As it is known, for many parents all moments connected with the birth of child (gestating, raising, or nurturing a baby, taking every day care) are a way more significant than a simple condition of genetic relationship. What is more, the compulsory DNA testing impose a lot of privacy risks. Jane Fortin assures that a national database listing the DNA details of every child on birth might fall into the wrong hands and expresses concerns about "a chance of creating an autocratic government with a dangerous ability to invade all individuals' privacy and generally compromise their autonomy".[263]

Taking into account this, Brigitte Clark states:

> Imperatives from the state will have negative impact for parents. If the legislator imposes an obligation on such parents to inform their children of the nature of their conception or ensure that the child is informed by means of birth certificate or a letter delivered when the child reaches a certain age, it will constitute an unjustifiable invasion of the privacy rights of future parents. Additionally, it could be discriminatory to such social parents, especially when compared with biological parents. This might discourage such couples from conceiving with the use of donor sperm and lead to a diminution of the number of couples having children via this method, thus depriving them of a family. Rather, tolerance, openness, and gradual acceptance of this method of conception over time are the only ways in which to create the notion of such an obligation to disclose.[264]

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[262] An Ravelingien, Guido Pennings, 'The Right to Know Your Genetic Parents: From Open-Identity Gamete Donation to Routine Paternity Testing", *The American Journal of Bioethics,* 13,5 (2013):34.

[263] Jane Fortin, "Children's Right to Know Their Origins - Too Far, Too Fast?", *Child and Family Law Quarterly* 21 3, (2009): 336-355, https://www.researchgate.net/publication/228236224_Children's_Right_to_Know_Their_Origins_-_Too_Far_Too_Fast.

[264] Brigitte Clark, "A Balancing Act? The rights of Donor-Conceived Children to Know Their Origins", Georgia Journal of International and Comparative Law 40,3 (2012):642, https://digitalcommons.law.uga.edu/cgi/viewcontent.cgi?referer=&httpsredir=1&article=1001&context=gjicl.

The meaning of this thoughts is that it is impossible to deal with such sensitive questions by imposing strict norms. “Where children do not suspect any differences in the circumstances of their conception, the children do not usually question their genetic origins. Openness and truthfulness in family relationships and respect for the child’s autonomy are ethical demands that are almost impossible to convert into a legal obligation.”[265] Contrary, the process of disclosure this information to the child should be a well-considered and weighted decision. In the best case scenario, it should be done with the assistance of family counselors and psychologists.

What is more, at present, “the implementation of genetic testing is not universally available and ready to be performed. Also nowadays this system is not so advanced to the stage at which all donor-conceived people could in theory use such services in case they wish to do so”.[266]

Trying to deal with the inaccessibility to the birth records Adoption Rights Alliance in Ireland have developed a guide, in which they cover the potential ways to receive this information under the EU General Data Protection Regulation (hereinafter - GDPR). Relying on the provision on Freedom of Information, it should be understood that not only birth parents have right to privacy but adoptees are also data subjects who have the same rights as other citizens in this regard. The adoption records constitute personal information of adopted individuals which particularly is “physical identity, such as physical condition and circumstances during early months and years, including place of birth, your care records, the names of the people responsible for care; genetic background and cultural and social identity, such as original name, natural parents’ names, your natural family members’ names and the other circumstances of adoption”. Hence, the adoptees (EU citizens) have the right to receive this information under the scope of GDPR provisions.[267]

Not only the mechanism contributing to the sharing information about genetic origins, but the environment and conditions of the disclosure should be well-considered. Crucially important in such circumstances is to choose the appropriate time for disclosure the truth about genetic origin. Researchers from the Centre for Family Research at Cambridge University in the UK support the opinion that children born following the use of donor insemination should be told about their origins

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[265] Brigitte Clark, “A Balancing Act? The rights of Donor-Conceived Children to Know Their Origins”, Georgia Journal of International and Comparative Law 40,3 (2012):642, https://digitalcommons.law.uga.edu/cgi/viewcontent.cgi?referer=&httpsredir=1&article=1001&context=gjicl.

[266] Sophie Zadeh, “Disclosure of donor conception in the era of non-anonymity: safeguarding and promoting the interests of donor-conceived individuals*?”, Human Reproduction* 31,11 (2016):2418, https://doi.org/10.1093/humrep/dew240.

[267] Claire McGetrick, “Information Guide for Adopted People”, 2019, accessed 20 march 2020, http://adoption.ie/wp-content/uploads/2019/11/ARA-Information-Guide_Nov-2019.pdf.

as soon as possible.[268] During the performed research, the participants were asked how they felt when they find out about the fact they were unnaturally conceived. A range of various feelings and emotions was introduced to them and they had to choose the one which they experienced at the moment of disclosure. And not surprisingly, the most common response from participants who had grown up in families which experienced donor conception was 'curiosity' not depending on the age. However, what really depended on the age was the indication of such fillings as 'confusion', 'shock', 'sadness', 'relief', 'frustration' or 'anger'. It showed that negative reaction was rather common among older people. One of the participants, a 30-year old, who found out at the age of 17, said that she regrets she was not informed about it much earlier. And the information she received was really hurting her feelings and sense of identity. A 19-year old who found out at the age of 12, said: "either tell your kid from the beginning or don't tell them at all, it was one of the most shocking and upsetting moments of my life". Consequently, it is considered that the early disclosure is far more preferable than situations where misattributed paternity comes to light once the person is a grownup.[269] Also earlier disclosure can prevent from the accidental discovery about the biological parent by the child.

Another risk which may appear during the disclosure is a potential misinformation which parents may intentionally or unintentionally say to the child. The survey recently obtained as part of studies of mothers of children conceived using anonymous and identifiable sperm donors in the UK has highlighted that "some women who have conceived under the legal requirement of donor anonymity describe the donor to their children as though he will be identifiable in the future, despite no knowledge of the donor having registered as identifiable under UK law".[270] Therefore, it is highly important to share only correct information. Disclosure that is based on misinformation about the donor's current legal status may not be the best safeguard of the interests of those who are donor-conceived.[271]

Sharing false information can create future unrealistic expectations for all family members. Parents who are advised to disclose information about donor conception with ideas about the non-existence of donor anonymity may further run the risk of fostering children's illusionary hopes.[272]

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[268] Kirsty Horsey, "Donor-conceived children should be told at an early age", Bionews, accessed 1 March 2020, https://www.bionews.org.uk/page_90731

[269] Kirsty Horsey, "Donor-conceived children should be told at an early age", Bionews, accessed 1 March 2020, https://www.bionews.org.uk/page_90731

[270] Sophie Zadeh, "Disclosure of donor conception in the era of non-anonymity: safeguarding and promoting the interests of donor-conceived individuals*?", Human Reproduction* 31,11 (2016):2418, https://doi.org/10.1093/humrep/dew240.

[271] Sophie Zadeh, "Disclosure of donor conception in the era of non-anonymity: safeguarding and promoting the interests of donor-conceived individuals*?", Human Reproduction* 31,11 (2016):2418, https://doi.org/10.1093/humrep/dew240.

[272] Sophie Zadeh, "Disclosure of donor conception in the era of non-anonymity: safeguarding and promoting the interests of donor-conceived individuals*?", Human Reproduction* 31,11 (2016):2418, https://doi.org/10.1093/humrep/dew240.

At the same time the one may ask: should the child be told about it at all if the disclosure will directly contradict best interest? This issue was regarded by the Strasbourg jurisprudence and we had noticed that child's best interest should be paramount. We are not denying the importance of providing the possibility to reveal the truth about genetic origins. Meanwhile the moment of disclosure is highly sensitive and requires special approach. There can also exist a danger that a donor-conceived child might wish to establish a relationship with the donor and then be rejected.[273] Hence, the psychological aspect of child reaction should be taken into account. All possible outcomes of such disclosure should be outweighed.

Along with progressive legislative achievements regarding recognition of the right to know one's genetic origin, actually very little is known about what happens when donors are identified, at least because of the fact that in several countries the law that has mandated identifiable donation is relatively new.[274] Particularly, in UK the flow of generation, which is be able to seek the origins, will emerge in 2023 (since those who was born in 2005 will reach 18 years). The same situation in Netherlands, where it will take until 2021 before the first donors who donated after the entry into force of the Wet donorgegevens will be confronted with a request to disclose their identity. In that year, the first donor-conceived children to whom the new system (introduced in 2004 and start to work in 2005) applies will have reached the age of 16. The annual reports of the Foundation note that the number of requests for information are increasing every year, especially with regard to requests from parents for non-identifying information. In 2015, the Foundation received 352 requests from parents for non-identifying information (compared to 261 requests in 2014, 35 requests in 2013 and 10 requests in 2006).[275] Moreover, tryouts to receive information about the donor are not always successful. Attempts to find the donor often are not so positive as it might be expected. The reason lays in the lack of communication about expectations and reality in donor's and offspring's contact.[276] What is more, the 'tracking' of the biological parent, who has no intention to maintain the contact with the offspring or, in worst case, can even be absolutely against it and willing to reject such contact, will turn into very harmful and unpleasant experience for the person.

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[273] Julie L. Sauer, "Competing Interests and Gamete Donation: The Case for Anonymity", *Seton Hall Law Review* 39,3 (2009):943.

[274] Sophie Zadeh, "Disclosure of donor conception in the era of non-anonymity: safeguarding and promoting the interests of donor-conceived individuals*?", Human Reproduction* 31,11 (2016):2418, https://doi.org/10.1093/humrep/dew240.

[275] Elodie Decorte, "Donor Conception: From Anonymity to Openness, Plurality and Diversity of Family Relations in Europe" in Plurality and Diversity of Family Relations in Europe, Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 158.

[276] Sophie Zadeh, "Disclosure of donor conception in the era of non-anonymity: safeguarding and promoting the interests of donor-conceived individuals*?", Human Reproduction* 31,11 (2016):2418, https://doi.org/10.1093/humrep/dew240.

Considering all the above, the disclosure of the information about origins is very sensitive issue both for parents, children and even donors. Surveys show that society still percept the disclosure of truth as something extraordinary rather that normal. While the practice of countries with policy of openness demonstrate that this perception can be changed as the indicators of disclosure become higher and higher every year. Results of researches and questioners of families which has gone through ART alongside with adoptive families show that it is important to know genetic roots. Whereas different mechanisms of mandatory disclosure allow to ensure that person would be told about genetic ancestry, it can be dangerous due to the fact that it is very unwanted intervention to the family private life. Yet there is no universal opinion about the exact way and age when the person should be informed. It is considered that the earlier – the better.

Suggested proposals of mandatory disclosure, such as reformation of birth registration system, routinely genetic testing still include a lot of unresolved issues, particularly private life matters. We would argue that the methods of ensuring the disclosure should be more gentle. Further, the concept of the ‘child best interest’ should not be left aside and considered as thoroughly as possible. The starting point should be proper psychological support of families, promoting more education in the regard of importance of genetic information and so forth.

# CONCLUSIONS

Genetic connections seem to be unnoticeable in our day-to-day routine. However, in one moment its significance turns to be enormous and that is why individuals, who due to the number of reasons are not aware of their genetic origins, should be provided with possibility to know the real situation concerning it. In this research, we have studied the current tendency of disclosure the information about genetic ancestry as a way of securing the right to know one's origins in selected European countries. And we definitely support the opinion that such openness should be promoted and legally established in nowadays legislations. Thus, we can conclude that:

1. Starting from the ethical justifications it is clear that the need to know biological parents is extremely important for the identity. Not less crucial is knowledge of genetic background for the maintaining health conditions and preventing dangerous diseases. All persons, whose genetic parents are unknown, should have a possibility to have an access to this information.
2. Having discussed the regulation of the right to know one's genetic origin in international legal acts we can conclude that none of them do not include a clear wording 'a right to know genetic origin'. However, this right is derivative from the broader scope of the right to identity, right to respect private and family life, right to information.
3. The State should be responsible for safeguarding the adherence of the right to know one's genetic origins. While studying examples of different European jurisdictions, we have become convinced that it is possible and, what is more, it has been actively implemented over the past years. Also we have noticed that all of the mentioned countries are following approximately one direction in the recognition of the right in question. They had established specialized institutions, which are responsible for the recording information (such as the HFEA in United Kingdom, Foundation for Donor Information in Netherlands, German Institute for Medical Documentation and Information (DIMDI)).[277] These institutions are responsible for gathering information and managing donor databases. They created a mechanism for access to this information for the offspring. The same idea of openness is maintained in the sphere of adoption.
4. The ECHR court practice maintains approach that the right constitutes person's vital interest, however it cannot be applied unquestioningly in every case. The right in question

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[277] Elodie Decorte, "Donor Conception: From Anonymity to Openness" in *Plurality and Diversity of Family Relations in Europe,* Katharina Boele-Woelki and Dieter Martiny (eds.) (Intersentia, 2019), 154.

is not understood as an unconditional right and therefore each case outcomes differ significantly due to various special circumstances. Interests of all the involved parties should be balanced together highlighting child's best interest. At the same time States as a guarantors of parties' rights are facing a big task of balancing those interests.

5. Analysis of the problem of donor's anonymity shows that this approach has been developing for a long time and still has its supporters. Even though, the donor anonymity has entitled to be reasonable in some cases, we believe that the necessity to know genetic origins prevails over statements in favor of donor's anonymity. It is fair that children will have the same power of decision making regarding the information about conditions of their birth and genetic parents. Donors and parents, who are insisting on donor's anonymity are weighing only their own interests and do not bear in mind what should be better for the child.
6. The key point is that countries should maintain unity in recognizing the right to know genetic origins. We thoroughly believe that as long as there are jurisdictions which allow to perform ART anonymously, the problem of establishing the right to know genetic origins will be relevant. Future parents will travel from country to country in order to avoid restrictions and therefore it will be impossible for the child to find the necessary information about genetic parents.
7. We have studied the complications which appear when it comes to the disclosure of this sensitive information to the child. And that is why the well-considered approach should be taken while the creating the legislative mechanism, which will enable offsprings to have access to the data of their genetic origins. While it is necessary to maintain unified attitude within the international community, the States has to be very careful in implementing strict imperatives for the disclosure.

## RECOMMENDATIONS

Considering all the mentioned facts in the present research we strongly support the necessity of recognizing the right to know one's genetic origins unconditionally and every right-bearer should have access to this information. However, the solutions and applied methods should be well-considered and balanced. In this regard, States have to become the guarantor of the right in question by introduction of the effective and accessible legal mechanisms. Particularly:

1. To abolish absolute donor anonymity in ART procedures in the legislations, where it still takes action. Even though the ban of anonymity does not mean automatic revealing to the offspring, at least, it creates a potential possibility to receive this information in future and simplifies all further search proceedings.

2. To establish donor registries in countries, where there are no ones, and ensure the cooperation between those, which already exist. Having discussed the current situation in Ukraine, we believe that it is necessary to create a Central Reproduction Center, which will be responsible for managing National Donor Register. In the long run, it is recommended to generate a common international registry, where the data from many local registries shall be collected and stored. That will be helpful for the persons, who were conceived in the countries other than their citizenship or residence, to get the information in flexible and time-saving way. It will be convenient if filling an application for the information from the international register could be conducted through the national registries. At the same time, it should be noted these registries should not store information about donors who already made donations on the terms of absolute anonymity. We have studied similar model in UK, where the level of disclosure directly depends on the year of the donation.[278]

3. To provide individuals, whose interest is at stake, with easy and barrier-free access to the information about their origins. In this regard, we consider that there is no need to set age limitations for the persons, who can file a request for the information. The question of the most appropriate moment for disclosure is very individual. It is reasonable to consider that person do not become adult in the mental sense directly after the moment of attaining the age of majority. That is why the age limit of disclosure cannot be connected with the age of legal capability as it involves emotional side. We believe that as soon as the person is informed, he or she can apply for this information.

4. To specify what kind of information could be disclosed. We consider the most reasonable option is sharing identifying information.

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[278] The HFEA official website, accessed 20 February 2020, https://www.hfea.gov.uk/.

5. To implement the policy of providing support for families. Particularly, counselling and consultations of family psychologists should be a necessary stage both during the preparation for ART and adoption procedures and when the child already starts to live in the family. While discussion the following problem in Sweden, Jane Stoll suggested to give the responsibility for psycho-social investigation to professional counsellors and establish a follow-up programs till the maturity of the offspring.[279] Hence, there is a way to go for further improvements and keeping safe mental condition of all involved parties.

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[279] Jane Stoll, "Swedish donor offspring and their legal right to information" (licentiate thesis, Uppsala University, 2008), 101, https://www.researchgate.net/publication/297916809_Swedish_donor_offspring_and_their_legal_right_to_information.

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# ABSTRACT

The present research is devoted to the concept and legal regulation of the right to know one’s genetic origins. Particularly, the paper contains approaches to understanding the right to know one’s genetic origins, defines mains stakeholders, and provides ethical justifications for the right in question. The legislative provisions and ECHR court practice are studied. The relevant problems are highlighted, such as donor anonymity, ‘reproductive tourism’, the moment of disclosure to the child, conflict of interests of involved parties and further relevant issues.

For the purpose of achieving the goals of the study, recommendations for legislative regulations were elaborated. General suggestions were formulated to build an effective approach to the provision concerning the right to know individual’s genetic origins. The conditions for such disclosure were discussed and summarized.

**Keywords:** the right to know one’s genetic origins, donor anonymity, parentage, legal parents, genetic parents, biological parents, ART, offsprings.

## SUMMARY

Structurally, the paper is divided into 3 Chapters: 1 – *The scope and content of the right to know one's genetic origin*, which explains the connection of increasing ART popularity with the latest trend towards openness. The concept and approaches to the right to know one's genetic origin are studied. The right-bearers are defined. The author studies the importance of the right to know one's genetic origins from the medical and socio-ethical perspectives and shows how the scope of the right to know one's genetic origins could be generated from the broader scope of conventional rights. 2 – *Enforcing the right to know one's genetic origin: legal framework and court practice.* This chapter provides examples of 5 countries, which has recognized the right to know one's genetic origins on the legislative level. The author studies the regulations regarding donor anonymity and the possibilities to receive information about offspring's birth or genetic parents. The author studies the gaps in Ukrainian legislation concerning ART and family law are highlighted. The provisions of draft laws on ART are mentioned. To support analysis of legislation, the author provides the ECHR court practice. 3 – *Problematic issues concerning the right to know one's genetic origin.* The author studies arguments in favor of the ban of the donor's anonymity and introduces its weak points. The attitude of donors and legal parents towards the ban of anonymity and their most common concerns related to the disclosure of their identity are shown. 2 popular models of anonymity are listed: French and Danish model. Also, the chapter covers the complications regarding balancing rights of all involved parties and the problem of 'reproductive tourism', which appears when future parents are trying to avoid the existing legislative restrictions and in this way put the right to know genetic origins in high risk. Lastly, the author discusses possible options to secure the disclosure by parents. Particularly the models of marks on birth certificates, DNA testing, an option for adoptees to receive the information using the GDPR provisions. The importance of choosing the right moment to disclose this sensitive information is explained. In the end, the author gives recommendations for ensuring the right to know one's genetic origins.

## HONESTY DECLARATION

11 May/2020
Vilnius

I, Kateryna Manetska, student of
*(name, surname)*

Mykolas Romeris University (hereinafter referred to University),

Faculty of Law, Joint Study Master Degree Programme in Private Law
*(Faculty /Institute, Programme title)*

confirm that the Bachelor / Master thesis titled

"The Right to Know One's Genetic Origin"
:

1. Is carried out independently and honestly;
2. Was not presented and defended in another educational institution in Lithuania or abroad;
3. Was written in respect of the academic integrity and after becoming acquainted with methodological guidelines for thesis preparation.

I am informed of the fact that student can be expelled from the University for the breach of the fair competition principle, plagiarism, corresponding to the breach of the academic ethics.

| | |
|---|---|
| Kateryna Manetska | Kateryna Manetska |
| *(signature)* | *(name, surname)* |