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The right of children to access their genetic material

I. Introduction

After thanking the organizers of this Conference for their kind invitation, which is a great honor to me, I would like to say that I am in the uncomfortable position of having to counter the respectable arguments of Professor Efi Kounougeri-Manoledaki, whose papers have inspired me to focus on the issue of genetic material donor disclosure. I admired the moderation of her arguments, a characteristic of wise teachers, who know very well that there is no absolute truth¹ in the gray zones of bioethics and that we only become wiser by exchanging our views.

In this presentation, I will not repeat my previous research on why a child has the right to know the donor's identity². Instead, I will limit myself to proving that children have the right to access any information related to their person and, consequently, to information on the donor of their genetic material. Furthermore, I will analyze the issues arising from different national legislation in relation to the right of genetic material donor disclosure, thus stressing the need for a uniform approach to the matter.

II. The ownership status of data

In order to decide on access rights, it is crucial to answer the question of who owns the data obtained from genetic material analysis.

A. The legal nature of data

Before investigating the ownership status of data, it would be appropriate to consider the legal nature of the data to which access is requested. This type of information has three aspects, as it is related to the genetic material donor, to the recipient (parent) and to the child

*I would like to thank *K. N. Christodoulou*, Associate Professor of the Law Faculty of the University of Athens for our very fruitful debates.

¹ *E.Kounougeri - Manoledaki*, an opponent of disclosing the genetic material donor's identity, very aptly accepts that "the arguments put forward by both sides are numerous and strong [...], no participant to these debates can be absolutely satisfied by his/her arguments". See *E.Kounougeri - Manoledaki*, Artificial insemination and Civil Law: The Draft Law on "Medical assistance in human reproduction", in: *E.Kounougeri - Manoledaki* (ed.), Artificial insemination and genetic engineering: The ethical and legal dimension, Northern Greece Law Society, Sakkoula Publications, Athens-Thessaloniki 2003, p. 85 et seq. (95).

² See *F. Panagopoulou-Koutnatzi*, The right of genetic material donor disclosure, in: *M. Kanellopoulou-Mpoti/F. Panagopoulou-Koutnatzi* (ed.), Bioethical Reflections, Papazisi Publications, Athens 2014, p. 199-248=Administrative Law Journal (Εφημερδα) 2014, p. 511-528.

being born. The donor's participation in the reproductive process through heterologous artificial insemination is a medical act and, therefore, it must be regarded, in the broader sense, as falling within the scope of health data and, in particular, of sensitive personal data within the meaning of Article 2(b) of Law 2472/1997. In addition, the fact that an individual may not be able to procreate naturally and may, therefore, resort to heterologous artificial reproduction methods, e.g. due to a medical condition, must be regarded as falling within the scope of health data and, consequently, of sensitive personal data within the meaning of Article 2(b) of Law 2472/1997. Finally, information on a person's origins is regarded as genetic data. This type of data may provide information as to the health status, predisposition to diseases or ethnic origin and, for this reason, it would be more appropriate to assume that these data fall within the category of sensitive personal data³.

The inclusion of this information in the category of sensitive personal data is not devoid of practical meaning, as it reflects the importance of maintaining the confidentiality of such data and providing the ability to lift such confidentiality for serious reasons. It is true that large stakeholders, such as insurance companies, employers etc., would like to have access to genetic data and, therefore, it is of utmost importance to ensure the confidentiality of this information.

Finally, given that genetic data are connected to many different individuals⁴, they may be reasonably characterized as data items with multiple connections.

³ See Hellenic Data Protection Authority, Decision 29/2012, available at: www.dpa.gr, accessed on: 14.2.2015. In this decision, the Authority accepts that, regardless of the special characterization of STR genetic loci as sensitive or simple personal data, their publication in a web page -even when such data remain published for a short period of time, in view of the fact that they may be stored, further processed and subsequently republished - undermines the right to privacy and, therefore, it should have been made upon authorization by the Authority, in accordance with the provisions of Article 7(2) of Law 2472/1997. However, due to the controversial views of the scientific community as regards the use of the informational value of STR genetic loci, the Authority imposed no administrative sanctions for the failure to obtain an authorization by the Authority. Note that decision No 44/2009 of the Hellenic Data Protection Authority, which was repealed on formal grounds (by means of Decision No 73/2011 of the Authority) (both available at www.dpa.gr, accessed on: 14.2.2015) had accepted that the STR genetic analysis must be regarded as sensitive personal data on health and/or racial or ethnic origin, in accordance with the provisions of Article 2(b) of Law 2472/1997. According to Opinion 15/2011 of the Supreme Court Prosecutor, *A.Kontaxis*, available at: http://eisap.gr/sites/default/files/consultations/gnom2011_0015.pdf, accessed on: 14.2.2015, genetic data are sensitive personal data. *I.D. Igglezakis*, *Sensitive Personal Data*, Sakkoula Publications, Athens-Thessaloniki 2004, p. 209, clearly states that genetic data fall within the category of medical data, i.e. sensitive data. The proposal for a Regulation of the European Parliament and of the Council on the protection of individuals with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation), available at: http://ec.europa.eu/justice/data-protection/document/review2012/com_2012_11_el.pdf, 25 January 2012, accessed on: 14.2.2015 recognizes the particular nature of genetic data, by placing them under special personal data categories. At the same time, Article 33(2) includes genetic and biometric data into the processing operations which are likely to present specific risks to the rights and freedoms of data subjects by virtue of their nature, their scope or their purposes.

⁴ See *K. N. Christodoulou*, *Privacy Law*, Legal Library Publications, Athens 2013, note in the margin 36, p. 19 *et seq.*

B. Data ownership-determination rights

It is very important to resolve the issue of data ownership, as it will allow for the practical identification of the data owner and, therefore, of the person entitled to have access to such data, given that all persons have the right to access their own data, which, in the field of personal data protection, is called “access right” (Vide Article 12 of Law 2472/1997). If it is accepted that the donor’s data also belong to the biological descendant thereof, in the sense that such data have multiple connections (i.e. they are connected both to the donor and to the biological descendant thereof), then the biological descendant has the right to access the data in question, given that they are associated to his/her person.

The views on the ownership status of data have their origins in the work of John Locke, stating that every person has the right to his/her individual sovereignty and, therefore, the right to control and own all products related to his person⁵. However, it must be noted that the ability to control genetic data does not automatically entail the acknowledgment of hereditary rights thereon, namely, industrial property rights. To avoid conceptual misunderstandings, it would be more accurate to say that every person has the right to determine his/her genetic data, arising from his/her right of informational self-determination⁶.

The case-law of foreign courts provides significant insight into data ownership. In the case of *Moore vs Regents of the University of California*⁷ the California Court of Appeal ruled that every person must have the ultimate power to control what becomes of his/her tissues, while acknowledging that the plaintiff, Mr. Moore, had property rights over his genetic material. In the case in question, Mr. Moore was submitted to a spleen removal operation. After the end of the operation, the doctors found that his cells had therapeutic properties. Without the patient’s knowledge and informed consent, they kept his spleen and created cell lines with specific characteristics for research-therapeutic purposes, with a view to their economic exploitation. Mr. Moore was asked to pay regular visits to the hospital for monitoring his health and taking biological material from his body. On the contrary, the Supreme Court of California⁸ ruled that Mr. Moore has no ownership rights over his biological material and denied the existence of liability in relation to the conversion of his cells. The Court held that the acknowledgment of an ownership right over genetic data is a political decision, which must be made by the legislator and not by the judge. This ruling

⁵ See L. Mitrou, Biobanks, research and genetic data, in: G.Maniatis-L. Mitrou, The protection of personal data, Sakkoula Publications, Athens-Thessaloniki 2008, p. 19 et seq. (34, footnote 40).

⁶ See L. Mitrou, *ibid* (footnote 5), p. 37 et seq.

⁷ See *Moore v. The Regents of the Univ. of California*, 215 Cal. App. 3d 709, 722, 249 Cal. Rptr. 494, 502 (1988).

⁸ See *Moore vs Regents of the University of California*, 51 Cal. 3d 120; 271 Cal. Rptr. 146; 793 P.2d 479 (1990).

made a clear distinction between the right to control genetic data and the claim for profit thereon⁹.

The case of the Icelandic biobank “Health Sector Database” is also worth mentioning when it comes to the issue of genetic information ownership. This biobank contained all medical data of Iceland’s population, including genetic and genealogical information for the genetic and epidemiological study of the Icelandic population. This interconnection led to the creation of a collective database, providing information on genotypes, genealogy and disease types. The purpose of this database was to reveal the relationship between genes and diseases, the pathogenesis of diseases, complications and their response to treatment. Iceland was not selected by chance for creating this type of biobank. The country was populated during the late 8th century by the Vikings and their Irish slaves and it has a small population, with low immigration flows. Therefore, Iceland’s population presents genetic uniformity, as two randomly selected individuals from the Icelandic population will have more genetically similar ancestors compared to two other individuals, randomly selected from a larger population sample¹⁰. In addition, since 1915, Iceland has a well-organized and reliable healthcare system. The Parliament of Reykjavik assigned to the company DeCodes Genetics, the task of collecting data on the 650,000 inhabitants of Iceland. The Swiss pharmaceutical company Hoffmann-La Roche had undertaken to pay to DeCodes Genetics the amount of two hundred million dollars for the exclusive use of its database in order to research twelve serious diseases, including schizophrenia, Alzheimer's disease, cardiovascular diseases etc. In addition to the serious objections formulated in relation to the issue of the participants’ consent, their inability to raise objections, their lack of information and the further use of their data, the question of concern to this paper relates to determining the owners of the collected data.

In the case under consideration, namely the case of the Health Sector Database, the Supreme Court of Iceland¹¹, held, in implementation of Directive 95/46/EC on personal data, that the father’s genetic data are also the child’s personal data. The Court acknowledged the

⁹ See *Maureen S. Dorney*, *Moore v. the Regents of the University of California: Balancing the Need for Biotechnology Innovation against the Right of Informed Consent*, *Berkeley Technology Law Journal* 1990, p. 333 *et seq.* (369).

¹⁰ See *E. Mallio*, *The human genome, Generic research and human rights protection*, Ant. N. Sakkoula Publications, Athens-Komotini 2004, p. 294 *et seq.* and footnote 668.

¹¹ See Icelandic Supreme Court, *Ragnhildur Guðmundsdóttir vs. The State of Iceland.*, No. 151/2003, available at: http://epic.org/privacy/genetic/iceland_decision.pdf, accessed on: 14.2.2015. In this case, the applicant sought the recognition of her right to prohibit the transfer of health data on her diseased father to a database. The Court held that the applicant cannot exercise this right by acting on behalf of her deceased father, but, in view of her right to privacy, she has legal interest in preventing the transfer of her father’s health data to the database, as the latter’s genetic data could lead to conclusions on the applicant herself.

applicant's right to prevent the inclusion of the medical records of her deceased father in the Icelandic Data base, as it held that the father's genetic data are also of interest to the child, as the latter inherits such data, in so far as they may provide useful genetic information in relation to the child.

C. The importance of ownership over genetic information

The findings made by the ruling of the Supreme Court of Iceland are very useful. Based on this ruling, it may be argued that the genetic data resulting from examining an individual may be regarded as personal data of the entire family, in so far as the members of this family are identifiable or have been identified¹². Therefore, the parent's genetic data are also the child's genetic data and, consequently, the child has the right to access them¹³ under Article 12 of Directive 96/46/EC. In application of this ruling, which, however, cannot lead to safe generalizations, the child could claim a right of access to the genetic material from which he/she was created and, probably, the donor may have a right of access to information on the result of the use of his/her genetic material. However, this is a complicated matter and needs to be further analyzed. It must not be overlooked that the ruling of the Supreme Court of Iceland may have been affected by the fact that the father, whose genetic data were assessed, was already dead and, therefore, he was no longer covered by the right to the protection of his personal data¹⁴. If the father, in his capacity as the subject of the data, was still alive, one could reasonable argue that he would have the right to the confidentiality of his data¹⁵. This debate becomes even more lively if we consider that, on the one hand, an individual may own his/her sensitive data (in this case the father) but, on the other hand, if his/her biological descendants also have ownership rights over the same data, then the descendants have the right to obtain knowledge of such data even if they are sensitive, as they may provide information on their person.

The above case-law can lead to many thoughts. Firstly, from the moment that genetic data is owned by someone, it follows that the owner has the right to access them. The question that follows is whether this access must be unlimited, thus leading to a disclosure of

¹² See *G. Laurie*, *Genetic Privacy-A challenge to Medico-Legal Norms*, Cambridge 2002, p. 253 *et seq.*

¹³ See *R. Gertz*, *An analysis of the Icelandic Supreme Court judgement on the Health Sector Database Act, 2004*, 1:2SCRIPTed 241, available at: <http://www.law.ed.ac.uk/ahrc/script-ed/issue2/iceland.asp>, accessed on: 14.3.2014.

¹⁴ Note that the provisions of Law 2472/1997 cover the personal data of living persons [see Article 2(c) of Law 2472/1997 in conjunction with Article 35 of the Civil Code, Opinion 4/2007 of the Group under Article 29 on the meaning of the term "personal data", 20.06.2007, pp. 27-28 and, *inter alia*, Decisions No 100/2001 and 32/2006 of the Authority]. Therefore, granting the sensitive personal data of a deceased person to a third-party [within the meaning of Article 2(i) of Law 2472/1997] does not fall within the provisions of Law 2472/1997.

¹⁵ See the relevant analysis of *M. Bottis*, *Anonymisation of Sperm Donors for Artificial Insemination: An International Data Protection Law Perspective*, IJEIL 2009, p. 69 *et seq.* (80), *op. cit.*

the genetic material donor's identity instead of a simple anonymous record, limited only to critical genetic information. It is considered that, in principle, the right of access cannot be exercised with restrictions¹⁶, namely, it cannot be restricted to an anonymous medical file as access relates not only to a person's genetic background but also to its evolution, i.e. the current situation of the parent. Descendants must have access both to impersonal genetic information and to its personal dimension. It is necessary for them to have all relevant information on their ancestors, as it is part of them.

In the end, the issue goes beyond the limits of legal science, as the basic underlying question is what the genetic elements that we actually inherit from our biological parents are¹⁷. The genetic material of biological parents is extremely useful to their children, as it may provide them with useful information on their life and evolution (e.g. predisposition to a specific disease).

III. The right of access to genetic information

The existence of a file is a prerequisite for implementing the legislation on the protection of personal data, in accordance with Article 3(1) of Directive 95/46/EC, and the Greek Law 2472/1997, transposing this Directive into Greek national legislation. In principle, the said file may only exist in the case of a fertility center or a genetic database. On the contrary, regardless of how much we choose to extend this concept, it would be impossible to consider that there is a "file" when children seek information from their own parents. In other words, in most cases, the mother does not keep a structured file on the identity of the child's father. Therefore, the legislation on the protection of personal data does not apply to the father-child relationship. On the contrary, this relationship is subject to the claims arising from the right to personal development. This means that the child has no right of access vis-à-vis the mother, with regard to disclosing the father's identity. Perhaps one could argue that the recognition of an access right in the case of medically assisted reproduction, but not in the case of the parent-child relationship, would create a situation of inequality between children born by medically assisted reproduction and children born by natural processes, as the former would have more rights than the latter. In particular, children born by heterologous assisted reproduction will be able to exercise their right of access to the data of their biological parent, while children born by natural reproduction will not have the same right, e.g. when the father is not who the mother claims him to be. The question arises as to whether children would have a right to know who their biological father is when the mother had extramarital

¹⁶ See *K. N. Christodoulou*, op.cit (footnote 4), note in the margin 194-195, p. 94 *et seq.*

¹⁷ See *M. Bottis*, op.cit (footnote 15), p. 81, *op. cit.*

relationships¹⁸ Assuming that children have a right to know their biological ancestors, arising from their right to personal development, then, if the mother had an extramarital relationship, children would be entitled to know that their alleged father is not their biological father. However, they would not be able to claim access to the biological father's data relying on the legislation on the protection of personal data, as the mother holds no structured file. On the other hand, this finding cannot give rise to a failure to recognize the access rights of a specific population group that complies with the conditions for implementing the legislation on the protection of personal data. The fact that a specific population group is covered by the legislation on the protection of personal data, while another is not, constitutes a specific legislative choice which, nevertheless, cannot result in lifting the protection for those enjoying the said right for reasons of equality with those who are not. Furthermore, we must not forget that the non-applicability of the legislation on the protection of personal data due to the lack of a structured file, does not lead to a failure to protect the child but to another type of legal protection. It could be well argued that, for reasons of equality, children born by natural reproduction must have the same rights as children born by heterologous artificial reproduction. Therefore, if the law allows the latter to have access to information on their genetic material donor, the former must have the right to access their father's identity, provided that the mother has presented another person as their father. In this case, there are clear practical difficulties with regard to discovering the truth. However, these difficulties cannot prevent the recognition of this right.

IV. Issues arising due to differences in national legislation

The right of access to the genetic material donor's information is further reinforced considering the general problems related to the right of disclosure, when the disclosure of the donor's identity is requested by a national of a country recognizing such disclosure as a right of the child, e.g. the Netherlands, but when the donor comes from a country that prohibits disclosure, e.g. Greece. In order to better understand this example, the question is what will happen if a child is born in the Netherlands, where disclosure is permitted, but the donor lives in Greece, where disclosure is prohibited.

If we limit the problem to the European Union, the answer lies in Directive 95/46/EC. In Article 4 of the Directive, it is stipulated that the applicable law is the one of the country where the controller is established, namely the fertility center providing the genetic material.

¹⁸ Cf. P. Lee Chang, D. Buccafurni-Huber, On the Moral Asymmetry of Gametic Contributions, *The American Journal of Bioethics* 2013, 56 *et seq.* (56). The authors argue that when the child's legal father knows that the child born is not his own child but the result of an extramarital relationship of the mother, the child does not have the right to be informed of the mother's behavior.

Therefore, in the example provided above, the applicable law is the Greek law, as the fertility center is established in Greece. However, the law of the country where the controller is established applies without prejudice to the fact that the legislation of the controller's country must be in line with the general framework of the Directive.

In my view, the failure of the controller's country of establishment to allow for disclosure restricts the right of access of individuals to data with multiple connections, given that the parent's genetic data are, in a broader sense, the individual's own data. In short, the prohibition of disclosure constitutes a restriction of the access right enshrined in Article 12 of Directive 95/46/EC. Note that we are talking about a restriction and not a prohibition, given that the Greek law allows for access to an anonymous medical record, but not to the donor's name. However, it is true that the limited access¹⁹ to the donor's medical record does not fully serve the right of protection of the child, as the said right would be better served if access to the donor's clinical picture was permitted. For instance, if the patient suffers from a rheumatic disease it would be useful to know the clinical evolution of the donor, which relates to the current state in which the donor is found and may be affected by the donor's geographical location (northern or southern regions, humid or dry climate etc.). Therefore, the restriction of the right to access is not fully compatible with Directive 95/46/EC.

In short, this argument could be summarized as follows: If the reproduction center is established within the EU, then Directive 95/46/EC must apply. On the contrary, if the reproduction center is not established within the EU, the case must be resolved using the provisions of private international law. According to Article 26 of the Civil Code, tort liability is governed by the law of the country where the offense was committed, and, consequently, the law of the country where the controller (i.e. the fertility center) is established shall apply. This rule applies without prejudice to public policy, according to Article 33 of the Civil Code.

V. Conclusion

The disclosure right of the genetic material donor's identity arises from the right of individuals to access information in relation to their person, as established by Article 5(A) of the Greek Constitution (Right of Information). This right is a more specific expression of the general right to information, as compared to the disclosure right, whereas it constitutes a prerequisite for the expression of informational self-determination²⁰. Any access to the individual's personal data, which are connected to the parent's data, must have the form of

¹⁹ Contrary to the right of disclosure, the right of access is not subject to any limitation. See *K. N. Christodoulou, op.cit* (footnote 4), p. 94 *et seq.*

²⁰ See *P. D. Armamento/V. A. Sotiropoulos, Personal Data, Interpretation of Law 2472/1997*, Sakkoula Publications, Athens-Thessaloniki 2005, p. 340, note in the margin 743.

full access, namely it must comprise the disclosure of the genetic material donor's identity and must not be restricted to an anonymous file of critical genetic information, given that access lies not only in an anonymous genetic record, but also in its evolution, namely the donor's current state. It seems inconceivable that someone may have access to an enormous amount of information on one's person but not to the identity of one's parent. Note that the disclosure of the donor's information must take place only under the condition that the intended donor knows, in advance, that his identity will be disclosed to the child. Therefore, there will be no breach of the intended donor's privacy, as donors themselves will be able to decide on whether to donate their genetic material or not, knowing in advance that their identity will be disclosed.

