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## **Free access to genetic testing – guaranteeing or threatening the right to privacy?\***

*Tomasz Sroka PhD*

Department of Bioethics and Medical Law, Jagiellonian University (Krakow, Poland)

DOI: 10.14679/1097

**Sumario / Summary:** 1. Introduction. 2. Genetic tests and protection of private life. 3. Direct-to-consumer genetic tests and threats to protection of private life. 4. Possibilities of elimination of threats to protection of private life in the sphere of direct-to-consumer genetic tests. 5. Direct-to-consumer genetic tests and protection of private life of others. 6. The necessity of physician's order on genetic tests.

**Resumen / Abstract:** El desarrollo del mercado de pruebas genéticas comerciales permite el acceso gratuito a ellas para un número ilimitado de personas. Todo el mundo puede realizar pruebas genéticas con cada proveedor de servicios médicos elegido y recibir resultados interesantes. Además, la transferencia de material genético para las pruebas y los resultados de éstas, pueden enviarse por correo sin una visita personal al proveedor del servicio. Teóricamente, el acceso libre a pruebas genéticas puede evaluarse como una garantía del derecho a proteger la vida privada. Todo el mundo puede recibir información detallada sobre su persona, en particular en el campo de la salud y las enfermedades existentes o potenciales. Por lo tanto, las pruebas genéticas brindan la oportunidad de ampliar el alcance de la información sobre el estado de salud. Lo que es más importante, esta información puede permitir, por ejemplo, elegir el tratamiento adecuado o tomar algunas decisiones preventivas. En este contexto, incluso el Tribunal Europeo de Derechos Humanos trata el acceso a las pruebas genéticas como una forma posi-

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\* Article received on May 9, 2017 and accepted for publication February 5, 2018.

ble de garantizar el derecho a proteger la vida privada (por ejemplo, pruebas genéticas prenatales). Sin embargo, el libre acceso a las pruebas genéticas también está relacionado con la amenaza al derecho de proteger la vida privada. La posibilidad de enviar el material biológico para la prueba por correo y el fácil acceso a este material abre amplias posibilidades para recibir los datos genéticos de cualquier persona. Este método de realizar pruebas genéticas no permite evitar la obtención de datos confidenciales de otra persona sin su conocimiento y consentimiento. Además, los servicios de asesoramiento para personas que realizan pruebas genéticas de forma privada no existen. Los pacientes no pueden recibir la interpretación adecuada de los resultados de las pruebas genéticas obtenidas comercialmente. Los resultados malinterpretados de las pruebas genéticas pueden tener un impacto muy negativo en la vida, en decisiones vitales y, en consecuencia, en la realización del derecho a proteger la vida privada. Por lo tanto, la admisibilidad de realizar pruebas genéticas comerciales, en particular la realización por correo, requiere un equilibrio adecuado entre las garantías y las amenazas al derecho a proteger la vida privada. La protección adecuada de este derecho probablemente requiera que las pruebas genéticas directas al consumidor solo se realicen por orden de un médico.

The development of market for commercial genetic testing allows free access to them for an unlimited number of people. Everyone can carry out genetic tests in every chosen medical service provider and receive interesting results. Moreover, the transfer of genetic material for testing and the results of these tests may be sent by post without a personal visit in the service provider. Theoretically, free access to genetic tests can be assessed as a guarantee of the right to protect private life. Everyone can receive detailed information about his person, in particular in the field of health and existing or potential diseases. Therefore, the genetic tests give the opportunity to broaden the scope of information about the state of health. What is more important, this information can allow, for instance, to choose appropriate treatment or to make some preventive decisions. In this context, even the ECHR treats the access to genetic testing as a possible way to guarantee the right to protect private life (for example prenatal genetic testing). However, free access to genetic tests is also connected with the threat to the right to protect private life. The possibility of sending the biological material for testing by post and the easy access to this material opens wide possibilities for receiving the genetic data of any person. This method of conducting genetic tests does not allow to prevent from obtaining the sensitive data of another person without his/her knowledge and consent. Furthermore, the advisory services for people conducting genetic tests privately does not exist. Patients cannot receive the proper interpretation of the results of genetic tests obtained commercially. Misinterpreted results of genetic tests may have the very negative impact on the life, on life decisions, and consequently on the realization of the right to protect private life. Therefore, the admissibility of conducting commercial genetic testing, in particular conducting by post, requires an appropriate balance between guarantees and threats to the right to protect private life. The proper protection of this

right probably requires that direct-to-consumer genetic tests probably should be done only on the order of a physician.

**Palabras clave / Keywords:**

Pruebas genéticas directas al consumidor / Protección de la vida privada / Asesoramiento genético / Consentimiento informado / Acceso no autorizado a la información personal.

Direct-to-consumer genetic tests / Protection of private life / Genetic counseling / Informed consent / Unauthorized access to personal information.

## 1. Introduction

On websites, both in Poland and in other European countries, one can find a lot of offers of genetic testing services directly, that is without the assistance of a physician (direct-to-consumer genetic testing). These tests are commercial in nature and can even be performed in laboratories outside the European continent, after sending a sample of genetic material by mail. The development of the market for commercial genetic testing (direct-to-consumer genetic testing) is also connected to their placing among the Treaty freedoms, in particular freedom of movement of goods and services<sup>1</sup>. Unfortunately, most European countries don't have legislation that was created specifically to regulate direct-to-consumer genetic tests<sup>2</sup>.

The range of genetic tests available direct-to consumer is very broad, from tests for confirmation or refutation of paternity or maternity, through tests for single-gene disorders, to tests for predisposition to diseases<sup>3</sup>.

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<sup>1</sup> See VAN HELLEMONDT, R.E. / HENDRIKS, A.C. / BREUNING, M.H., "Regulating the use of genetic tests: is Dutch law an example for other countries with regard to DTC genetic testing?", *Amsterdam Law Forum*, Vol. 3, 2011, pp. 18-19.

<sup>2</sup> See KALOKAIRINO, L. / HOWARD, H. C. / SLOKENBERGA, S. / FISHER, E. / FLATSCHER-THÖNI, M. / HARTLEV, M. / VAN HELLEMONDT, R. / JUŠKEVIČIUS, J. / KAPELAŃSKA-PRĘGOWSKA, J. / KOVÁČ, P. / LOVREČIĆ, L. / NYS, H. / DE PAOR, A. / PHILLIPS, A. / PRUDIL, L. / RIAL-SEBBAG, E. / ROMEO CASABONA, C.M. / SÁNDOR, J. / SCHUSTER, A. / SOINI, S. / SØVIG, K.H. / STOFFEL, D. / TITMA, T. / TROKANAS, T. / BORRY, P., "Legislation of direct-to-consumer genetic testing in Europe: a fragmented regulatory landscape", *Journal of Community Genetics*, 18 November 2017; SPRUMONT, D. / BORRY, P. / SHABANI, M., "Genetic Testing in Europe. An Overview of the Legal Framework", *European Health Law*, DEN EXTER, A. (Ed.), Maklu, Antwerp, Belgium, 2017, p. 385-387.

<sup>3</sup> See "ASHG Statement on Direct-to-Consumer Genetic Testing in the United States", *The American Journal of Human Genetics*, Vol. 81, 2007, p. 635; SU, P., "Direct-to-Consumer Genetic Testing. A Comprehensive View", *Yale Journal of Biology and Medicine*, No. 86, 2013, p. 360-361.

Therefore, the scope of information which can be acquired from genetic tests is also very broad.

It is worth mentioning that there are two types of genetic tests performed commercially. First, there are the do-it-yourself kits with which the person concerned samples genetic material and conducts its analysis by himself using a special kit sent by the service provider. The test results are obtained immediately and directly by the person concerned. Secondly, there are the so-called home sampling tests with which the person concerned samples genetic material by himself, but the genetic material for testing is sent to the laboratory. The laboratory, after testing, sends the results of the analysis of the samples submitted back to the person concerned<sup>4</sup>.

Both types of genetic tests give the individual an opportunity to obtain a wide range of information not only on his genes, but also on the genes of other people (because of their heredity) without leaving home, and sometimes without the need to provide a sample of genetic material to an appropriate laboratory. The nature of the information and closeness of the relationship with the sphere of human privacy requires an analysis of how much the access to commercial genetic testing is a guarantee, and how much a threat to the right to privacy of the individual.

## 2. Genetic tests and protection of private life

Free access to commercial genetic testing is not limited to the ability of an individual to exercise the right to know his genetic identity and information directly related to one's genes. Genetic tests are in fact important for other aspects of private life, especially health and existence of potential diseases, as well as decisions concerning therapeutic and prophylactic actions. Genetic tests provide for a possibility to better understanding oneself, and above all, one's state of health and the likelihood of developing e.g. cancer, Alzheimer's disease or a genetic disease. The information obtained may allow, among others, the selection of adequate treatment (e.g. information about drug responses) and making informed decisions about prevention, e.g. in the selection of diet reducing the risk of diseases, thus allowing even more conscious shaping of one's private life<sup>5</sup>.

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<sup>4</sup> See VAN HELLEMONT, R.E. / HENDRIKS, A.C. / BREUNING, M.H., "Regulating...", p. 14; KAPELAŃSKA-PREGOWSKA, J., *Prawne i bioetyczne aspekty testów genetycznych*, Warsaw, Poland, 2011, p. 288.

<sup>5</sup> See BAIR, S., "Direct-to-Consumer Genetic Testing: Learning from the Past and Looking toward the Future", *Food and Drug Law Journal*, Vol. 67, 2012, p. 424; SCHLECKSER, K., "Physician participation in direct-to-consumer genetic testing: pragmatism or paternalism?", *Harvard Journal of Law and Technology*, No. 2, 2013, p. 697 and 703; SPECTOR-BAGDADY, K. / PIKE, E., "Consuming Genomics: Regulat-

Under the European Convention on Human Rights the protection of private life does not only encompass the right to be left to oneself, but also the right to obtain information about oneself. It seems that part of such a right is the possibility of obtaining the information resulting from genetic testing<sup>6</sup>. Such statement arises from the interpretation of the European Convention on Human Rights in the context of the 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), in particular Article 16 of the Additional Protocol on Genetic Testing for Health Purposes<sup>7</sup>. Since is the right to know any information obtained from genetic tests is a component of the protection of private life, then the right of an individual to carry out relevant tests to obtain genetic information is even more a part of such protection.

Moreover, in its case law the European Court of Human Rights stressed the importance of access to genetic testing as an instrument for the guarantee under Article 8 of the European Convention on Human Rights<sup>8</sup>. In the case of R. R. against Poland, the Court noted that access to prenatal genetic testing in a timely manner as a guarantee for genetic medical services, allowing to determine the health state of the fetus<sup>9</sup>. Thus, access to genetic tests - in some cases - may be an instrument to ensure protection for the right to privacy under Article 8 of the European Convention on Human Rights.

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ing Direct-to-Consumer Genetic and Genomic Information”, *Nebraska Law Review*, Vol. 92, 2014, p. 685 and 689.

<sup>6</sup> See BORRY, P. / VAN HELLEMONDT, R.E. / SPRUMONT, D. / FITTIPALDI DUARTE JALES, C. / RIAL-SEBBAG, E. / SPRANGER, T.M. / CURREN, L. / KAYE, J. / NYS, H. / HOWARD, H., “Legislation on direct-to-consumer genetic testing in seven European countries”, *European Journal of Human Genetics*, Vol. 20, 2012, p. 715.

<sup>7</sup> Article 16 –Respect for private life and right to information

1 Everyone has the right to respect for his or her private life, in particular to protection of his or her personal data derived from a genetic test.

2 Everyone undergoing a genetic test is entitled to know any information collected about his or her health derived from this test.

The conclusions drawn from the test shall be accessible to the person concerned in a comprehensible form.

3 The wish of a person not to be informed shall be respected.

4 In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraphs 2 and 3 above in the interests of the person concerned.

<sup>8</sup> Everyone has the right to respect for his private and family life, his home and his correspondence.

<sup>9</sup> Application no. 27617/04, 26 May 2011.

Consequently, it can be concluded that the possibility of using commercial genetic testing is for the individual a way to guarantee the protection of private life, because they allow a greater understanding of information about oneself, and thus more conscious shaping of one's private life. People can be proactive in making their own health care decisions<sup>10</sup> and tests could allow individuals to take greater responsibility for safeguarding their own health<sup>11</sup>.

### 3. Direct-to-consumer genetic tests and threats to protection of private life

However, free access to genetic tests is also associated with a risk to the protection of privacy of the individual. The literature emphasizes the fact that a large group of genetic tests is of questionable (disputed) quality. This is due to the fact that many of them are not pre-verified in clinical trials<sup>12</sup>. Consequently, their impact on the private lives of individuals can be negative, because unfavorable results may lead to deterioration in the health of a patient, particularly mental, and groundless treatment or change style life. The right to information on the private sphere of a person must therefore be realized with respect to the need to protect the person from wrong genetic information.

Guarantees related to the protection of human rights, in particular the right to protect private life, impose a positive obligation to protect individuals from the dangers mentioned above on the state, in particular at the level of legislation. For this reason, both the European regulations and literature emphasize that genetic tests should be carried out only after meeting certain requirements relating to the principles of informing the person conducting the genetic tests. According to Art. 8 of the Additional Protocol on Genetic Testing for Health Purposes to the Convention on Human Rights and Biomedicine, a person undergoing genetic testing should be previously informed of the purpose and nature of the test and the expected results<sup>13</sup>.

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<sup>10</sup> See FARKAS, D.H. / HOLLAND, C.A., "Direct-to-Consumer Testing. Two Sides of the Coin", *Journal of Molecular Diagnostics*, No. 4, Vol. 11, 2009, p. 263.

<sup>11</sup> See KAYE, J., "The regulation of direct-to-consumer genetic tests", *Human Molecular Genetics*, Review Issue 2, Vol. 17, 2008, p. 180.

<sup>12</sup> See BAIR, S., *Direct-to-Consumer...*, p. 419; HAUSKELLER, C., *Direct to consumer genetic testing*, *BMJ* 2011; 342:d2317. See also SLOKENBERGA, S., "Direct-to-consumer Genetic Testing: Changes in the EU Regulatory Landscape", *European Journal of Health Law*, Vol. 22, 2015, pp. 467-468.

<sup>13</sup> When a genetic test is envisaged, the person concerned shall be provided with prior appropriate information in particular on the purpose and the nature of the test, as well as the implications of its results.

This regulation indicates that the European legislator recognizes the need to ensure that appropriate information on the nature of the test, the quality and the expected results are communicated to the person concerned before carrying it out. However, the obligation to provide information should not end on the characteristics of a genetic test which is to be made. Also, the recipient of the results of the test may not be left to himself, but should be granted the opportunity to benefit from genetic counseling, in which a qualified person, especially a physician, shall interpret the test results. The model of direct-to-consumer tests is criticized for the absence or dubious quality of post-test information and genetic counselling<sup>14</sup>.

It is also worth to mention that direct-to-consumer tests pose a potential threat to the model of informed consent for medical services which is one of the guarantee of the protection of private life. Although consumers are informed about the testing process, this information is not a substitute for a conversation with a physician about risks and benefits of genetic tests. Very often the information presented on websites is written to persuade to conduct tests. Sometimes there is a lack of information about possible, alternative methods of diagnosis or the presented information may be misleading<sup>15</sup>. Meanwhile, only a correct and full range of information is a condition sine qua non of a proper consent for every medical procedure, including genetic tests.

#### **4. Possibilities of elimination of threats to protection of private life in the sphere of direct-to-consumer genetic tests**

A threat to the proper realization of the right to protection of private life associated with the poor quality of the commercial genetic testing or insufficient knowledge of the people undergoing it on the nature of genetic tests and how to interpret the results is therefore possible to eliminate. Firstly, it is the obligation of commercial genetic testing service providers to always inform the persons concerned, before performing the tests, of their essence, quality, expected results and how to interpret them, in order to fully implement the guidelines of Article 16 of the Additional Protocol on Genetic Testing for Health Purposes to the Convention on Human Rights and Biomedicine. It seems that this condition is generally realized. Analysis of samples of offers of service providers engaged in the performance of commercial genetic testing shows that they are trying to honestly fulfill the required disclosure, prior to the execution of a genetic test.

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<sup>14</sup> See BORRY, P. / VAN HELLEMONDT, R.E. / SPRUMONT, D. / FITTIPALDI DUARTE JALES, C. / RIAL-SEBBAG, E. / SPRANGER, T. M. / CURREN, L. / KAYE, J. / NYS, H. / HOWARD, H., "Legislation...", p. 715.

<sup>15</sup> See BAIR, S., *Direct-to-Consumer...*, pp. 417-418.

It is also necessary to create a system of genetic counseling in which each person who has undergone genetic testing, would be able to obtain detailed information on how to interpret the results from a competent person, preferably a doctor, and be suggested a medical and preventive follow-up<sup>16</sup>, what is emphasized under Art. 8 Additional Protocol on Genetic Testing for Health Purposes to the Convention on Human Rights and Biomedicine<sup>17</sup>. In this respect, a threat to proper protection of the private sphere is greater, because for example in Poland, a satisfactory system of genetic counseling has not yet emerged. At the same time general practitioners often do not have enough knowledge to provide reliable analysis of the patient's test results. As a result, often the persons performing genetic tests by themselves are then left to themselves to deal with their results, which may lead to unjustified actions in the sphere of private life and, therefore, constitute - in a sense – a violation of the state's obligation to respect the private life of the individual.

##### **5. Direct-to-consumer genetic tests and protection of private life of others**

The danger to protection of the privacy of individuals in the course of carrying out commercial genetic testing occurs primarily in connection with the necessity of processing of genetic information on a specific person, which are undoubtedly of sensitive data<sup>18</sup>, by a laboratory. Both the transmission of samples of genetic material by post, then processing the material and the results of tests in the laboratory, often located in a different country, as well as the transmission of test results by email or post to the person concerned, or even via telephone, cause danger of disclosure of information closely related the sphere of individual's privacy to unauthorized persons. There are real concerns that individual's personal genetic information might be used without the permission or even to the detriment of the individual<sup>19</sup>.

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<sup>16</sup> However, the role of a doctor is wider – a physician can not only help patients interpret results, but also help them decide whether to get tested in the first place – see SCHLECKSER, K., *Physician...*, p. 698 and 711-713.

<sup>17</sup> For predictive genetic tests as referred to in Article 12 of the Convention on Human Rights and Biomedicine, appropriate genetic counselling shall also be available for the person concerned.

<sup>18</sup> See art. 9 of Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation).

<sup>19</sup> See BAIR, S., "Direct-to-Consumer...", p. 425.

Generally, all service providers declare the protection of information related to genetic testing against third parties. However, the sheer fact of transferring sensitive information by email or post does not guarantee effective protection against disclosure to unauthorized persons, therefore it raises some threat to the protection of privacy of the individual. For this reason, it seems that people using commercial genetic testing should be additionally informed about the increased risk of leakage of information related to the tests and their results, resulting from such methods of delivery of genetic material and test results (traditional and electronic post) that do not ensure full protection of privacy of the individual. What's more, each state should adopt appropriate regulations, which would ensure adequate protection of data about genetic testing processed (collected) by companies and laboratories, especially after the conclusion of their activities associated with genetic testing<sup>20</sup>.

Free access to commercial genetic testing is also associated with the danger to the sphere of privacy of others than tested. In the literature it is noted that due to the nature of certain hereditary diseases or mutations of genes, in a simple way an individual can obtain data about the health of their family members. Such knowledge could affect the protection of their private sphere<sup>21</sup>. It seems, however, that due to the nature of the information contained in the genes, the risk of obtaining information about others through genetic testing is inevitable.

However, it is worth to consider if the person undergoing genetic testing (not just commercial), the results of which may relate to other people, should not be obligated to keep the results containing information relating to the sphere of private life others secret before obtaining them, like when it comes to the professional secrecy of health professionals. It appears that the benefits of a particular genetic diagnosis are such an important value that access to them should not be limited by this potential knowledge of the genetic information about other people. However, there should be sufficient guarantees for the protection of the autonomy of the private sphere of other people, including their right to ignorance.

The issue of protection of privacy of others can arise in particular when the genetic tests would be carried out in the confirmation or refutation of paternity or maternity, or of origin from common ancestors<sup>22</sup>. Commercial genetic tests may in fact be used as a way to circumvent existing certain prohibitions on determining the genetic origin of family members existing under the Polish law. For example, according to Art. 68 of Family and

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<sup>20</sup> See SU, P., "Direct-to-Consumer...", p. 362.

<sup>21</sup> See VAN HELLEMONDT, R.E. / HENDRIKS, A.C. / BREUNING, M.H., "Regulating...", p. 15.

<sup>22</sup> See SU, P. "Direct-to-Consumer...", p. 360.

Guardianship Code "Denial of paternity is not allowed if a child was conceived as a result of medical treatment approved by the mother's husband" and in accordance with Article 124 [1] of Family and Guardianship Code "If the adoptee's parents consented before the court of protection to his adoption without specifying the adoptive parent, then establishing the adoptee's descent by acknowledgment of paternity, judicial establishment or denial of his descent or invalidation of acknowledgment of paternity is not allowed". In turn, according to Art. 38 of the Act on the Treatment of Infertility, both a person born by the procedure of medically assisted procreation, as well as his legal representative, are not able to acquire information needed to identify the donor of germ cells or the embryo, though the legitimacy of the existence of such a prohibition is questioned in the literature.

Free access to genetic testing, and to genetic material of others, such as hair, can lead - without the knowledge and consent of the people concerned - to carrying out relevant tests to determine the family relationship from the biological point of view, despite the fact that regulations sometimes formally prohibit any interference or verification of existing family relationships.

This situation illustrates probably the greatest threat to the protection of the private sphere of individuals arising from the admissibility of the free conduct of commercial genetic testing, in addition it pertains to issues not necessarily related to health. The possibility to send samples of genetic material for research by mail, and even to conduct these tests independently using a device sent in by the service provider, as well as the ease to access biological material which allows to carry out some genetic tests (e.g. hair) open wide possibilities for acquiring genetic data of any person (so-called secret testing or DNA-theft). At the same time, today operating by mail order does not allow to prevent the obtaining of sensitive data of third parties against their will. Moreover, the offers of individual companies concerning e.g. establishing paternity or so-called tests of betrayal, openly encourage to obtain information about another person without their knowledge and consent, which constitutes an interference with their right to privacy.

## **6. The necessity of physician's order on genetic tests**

The manner of running the business of conducting commercial genetic testing does not allow for verification of the identity of the person requesting the execution of the test. In particular, laboratories do not have any instruments to check whether the person who sent the genetic material for testing, is also the person from whom the material was taken. Such a guarantee is not provided by the necessity to register via website forms before the conclusion of the relevant agreement, because the registration proce-

sure does not guarantee that the person placing the data into the system is the person whose data are filled in.

It seems, the protective mechanisms provided by both Chapter V and VI of the Additional Protocol on Genetic Testing for Health Purposes to the Convention on Human Rights and Biomedicine are not sufficient in this respect, as well as the demands formulated in relation to the principles of genetic testing in children and persons incapable of informed consent. European Society of Human Genetics stated that „special measures should be taken to avoid inappropriate testing of minors and other legally incapacitated persons”<sup>23</sup>, and in the literature also is also stressed that for the protection of privacy of minors, genetic tests on children, except in cases of emergency, should not be done until the minor will not be able to consciously participate in decisions relating to undergo genetic testing<sup>24</sup>. These regulations and proposals do not provide for effective protection against the possibility of genetic testing against the will of the person to whom these tests relate to, and also refer only to a narrow group of people exposed to the possibility of such tests (minors, persons unable to consent).

Therefore, consideration should be given to whether - in order to ensure adequate protection of the private sphere of individuals against unauthorized being subjected to genetic testing - these tests should not be done only on the order of a physician. The basis for such solution can be found in European legislation. According to Art. 8 of the Additional Protocol on Genetic Testing for Health Purposes to the Convention on Human Rights and Biomedicine, a genetic test for health purposes may only be performed under individualized medical supervision. In Germany, according to sec. 7 para. 1 of the Human Genetic Examination Act, a diagnostic genetic examination may only be undertaken by physicians<sup>25</sup>.

The need to obtain such an order would in fact guarantee that the person who contracts to carry out genetic testing really is a person in relation to which these tests - with his knowledge and consent - are to be per-

<sup>23</sup> See “Statement of the ESHG on direct-to-consumer genetic testing for health-related purposes”, *European Journal of Human Genetics*, Vol. 18, 2010, p. 1271.

<sup>24</sup> See HOWARD, H.C. / AVARD, D. / BORRY, P., “Are the kids really all right? Direct-to-consumer genetic testing in children: are company policies clashing with professional norms?”, *European Journal of Human Genetics*, Vol. 19, 2011, p. 1122.

<sup>25</sup> See BORRY, P. / VAN HELLEMONDT, R.E. / SPRUMONT, D. / FITTIPALDI DUARTE JALES, C. / RIAL-SEBBAG, E. / SPRANGER, T. M. / CURREN, L. / KAYE, J. / NYS, H. / HOWARD, H., “Legislation...”, p. 717; KALOKAIRINO, L. / HOWARD, H. C. / SLOKENBERGA, S. / FISHER, E. / FLATSCHER-THÖNI, M. / HARTLEV, M. / VAN HELLEMONDT, R. / JUŠKEVIČIUS, J. / KAPELAŃSKA-PREGOWSKA, J. / KOVÁČ, P. / LOVREČIĆ, L. / NYS, H. / DE PAOR, A. / PHILLIPS, A. / PRUDIL, L. / RIAL-SEBBAG, E. / ROMEO CASABONA, C.M. / SÁNDOR, J. / SCHUSTER, A. / SOINI, S. / SØVIG, K.H. / STOFFEL, D. / TITMA, T. / TROKANAS, T. / BORRY, P., “Legislation...”

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formed. It appears that currently only such a solution is able to provide the appropriate level of protection of privacy of individuals against unauthorized access to personal information by third parties as a result of carrying out commercial genetic testing without the knowledge and consent of the persons concerned.