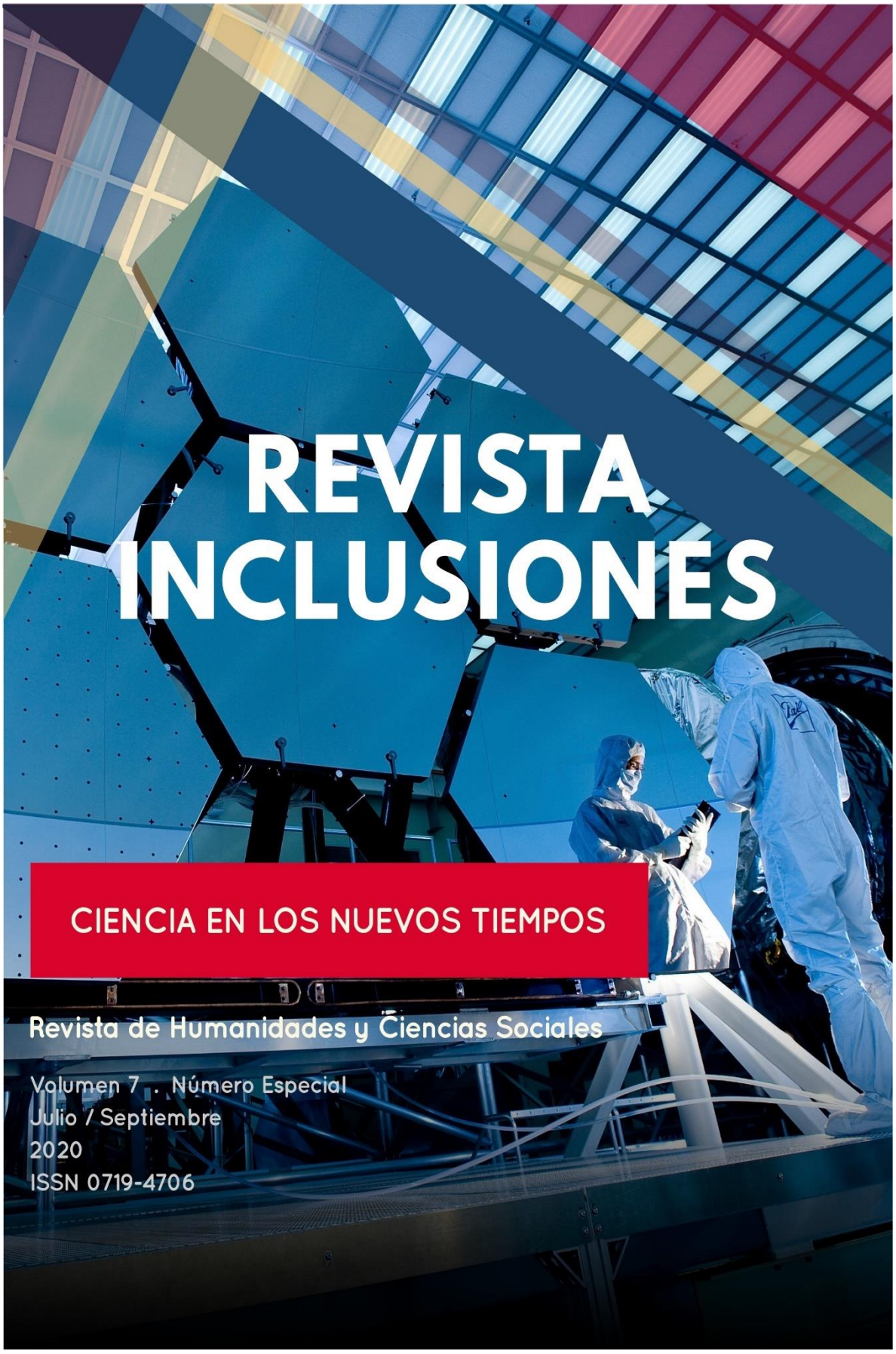

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ASPECTS OF THE DEVELOPMENT OF LEGAL REGULATION FOR GENETIC DIAGNOSTICS IN THE RUSSIAN FEDERATION

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Abstract

The need for jurisdiction in relations in the field of medicine, including genetic methods and research on humans, is determined by its very development and the emergence of the necessary legal regulation of relations regarding various aspects of the right to health and medical care and ending with the right to preserve information about human health, management, and control of this field. The development of genomic medicine is inextricably linked with two fields that are of fundamental importance for legal regulation in this area, namely gene diagnostics and gene therapy. Thus, having studied the Russian and foreign (national) legislation one can conclude that Russian legislation stands out by legal gaps and lack of unified standards.

Keywords

Genome – Genetic diagnostics – Genetic testing – Genetic counseling – Biomedical research

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Introduction

In recent years, in the world of biomedical science, based on the new generation of genetic technologies, one can witness the active development of treatment tools for complex rare (orphan) diseases, incurable hereditary, and acquired pathologies.

At present, Russian science can quickly learn from the successful global experience and provide Russia with a leading position in the application of new biotechnologies. In Russia, backlogs have been formed for most genetic technologies, including those in the field of genetic diagnostics and genetic editing. The presence of large research centers and well-trained highly qualified personnel will very soon provide the basis for scientific work of any complexity.

According to Decree No. 97 "On the fundamentals of the state policy of the Russian Federation in the field of ensuring chemical and biological safety for the period up to 2026 and the future perspective" issued by the President of the Russian Federation on March 11, 2019, several problems requiring solution were identified, including the following:

- implementation of the genetic certification of the population, considering the legal framework for protecting data on the personal human genome and the formation of the genetic profile of the population;

- development of the production of Russian laboratory equipment for microbiological research, including molecular genetic research;

- improvement of legal regulation in this area;

- accession of the Russian Federation to the Nagoya Protocol on Access to Genetic Resources.

At the same time, the state sets the most important task for itself to ensure the safety of applying the results of biotechnological research. Thus, it seems that a system of control over the activities of organizations involved in such studies is needed, as well as an assessment of risks in the use of genetic technologies.

In this connection, it seems necessary to improve the legal, regulatory, and methodological framework for the development of genetic technologies and to harmonize the regulatory framework in genome research, as well as in applying the results of such research in medical practice.

Methods

Let us review the international legal experience of regulation in the field of biomedical technologies, in particular genetic diagnostics, and the stages of development of such regulation in Russia in this area.

PhD in Law L.N. Vasilyeva[1] identifies two global existing positions in the world in the legal regulation of public relations in the field of biotechnology. The first is the establishment of legal norms characterizing the legal regime of the final product, regardless of the technological process of manufacture of this product (the USA and Canada). The second is the establishment of standards governing the technological process and methods of production of the final product (the European Union). Doctor of Law, Professor G.B. Romanovsky, when comparing the legal regulation of genetic research in Russia and abroad, points out the safety priority in German law, which is implemented through the creation of a central biosafety commission, including experts in microbiology, cell biology, virology, genetics, breeding, ecology, and others and representatives of organizations in the field of industrial safety, agriculture, consumer protection, and others. At the same time, the commission is charged with making recommendations in the field of security issues, its recommendations are to be published in the Federal Gazette. At the same time, Romanovsky notes that with the American experience in monitoring the conduct of genetic research, each protocol of the future procedure is considered by the institution's biological safety committee. If the protocol is approved, it is sent to the advisory committee of the National Institute of Health (NIH) and then reviewed by the national service that monitors food and drug safety. After appropriate approval, the protocol is also published in the Human Gene Therapy[2] journal. This example shows that control in American practice is built within the framework of internal and departmental (political) control.

The international legal position concerning genetic research is to reflect the interests of the global community in controlling the use of a biotechnological product. Thus, the Helsinki Declaration "Recommendations for Doctors on Biomedical Research in Humans" (adopted by the 18th World Medical Assembly, Helsinki, Finland, June 1964), unconditionally establishes human interests and human rights as the legal regulation center. However, at the same time, it gives the doctor the right to apply new diagnostic and therapeutic methods when treating the patient, if, in their opinion, these methods give hope for saving lives, restoring health, or can alleviate suffering.

In 1997, at the European level, the Convention on the Protection of Human Rights and Dignity of the Person in Connection with the Application of Biology and Medicine (the Oviedo Convention) was adopted, which is seen as the legal protection of the dignity of the individual from possible misuse of the achievements of scientific progress. In the same year, the Universal Declaration on the Human Genome and Human Rights was adopted. It should be noted that the Convention on Human Rights and Biomedicine adopted three additional Protocols: the Protocol against cloning, the Protocol on transplantation of human organs and tissues, and the Protocol on Biomedical Research.

There is also experience in decision-making by the Inter-Parliamentary Assembly of the CIS member states that are directly related to the area under consideration: "On the ethical and legal regulation and safety of genetic medical technologies in the CIS member states". Thus, on November 18, 2005, the Model Law "On the Protection of Human Rights

[1] L. N. Vasileva, Biotekhnologii i fundamentalnye prava cheloveka: vektory I predely pravovogo regulirovaniya. Pravo v epokhu biotekhnologii: sbornik materialov studencheskoi konferentsii. (Moscow: The Institute of Legislation and Comparative Law under the Government of the Russian Federation, 2018), 23.

[2] G. B. Romanovskii, “Pravovoe regulirovanie geneticheskikh issledovanii v Rossii i za rubezhom”, Sravnitelnoe pravo MGYuA num 7 (2016): 93-102.

and Dignity of a Person in Biomedical Research in the CIS Member States" was adopted. This law is of great importance for Russian rulemaking, in our opinion, since it contains for the first time the concept of biomedical research (a study with the participation of a person conducted to research new diagnostic, therapeutic and/or prophylactic means and methods of obtaining new knowledge in human physiology and psychology in conditions of the norm, pathology, and extreme situation).

Besides, the law extends to citizens of the state, foreign citizens, and stateless persons who are in the territory of the state participating in biomedical research and applies to all institutions and persons related to conducting biomedical research in the state. The Model Law applies to all types of biomedical research involving humans, including those carried out on in vivo embryos, but excluding studies on in vitro embryos. Under Article 4 of this law, state policy in the field of protecting the rights and dignity of a participant in biomedical research is aimed at creating conditions for protecting their health, receiving medical care that meets modern scientific and practical achievements, and preventing the possibility of discrimination during the research[3].

The law also enshrines the principles of state policy to protect human rights and dignity in biomedical research (Article 4), the rights of participants in biomedical research (Article 5), the regulation of the safety of such research (Chapter 2), the status of the ethics committee and the importance of the expertise it performs (Chapter 3). From the above legislation, it follows that the necessary "legal reserve" exists in the form of the experience of legislative activity in other countries, which can be used for successful law-making in the field of genomic research in Russian law.

Leading Researcher of the Department of Constitutional Law, Institute of Industrial and Social Protection, PhD L.N. Vasilyeva defines the following stages in the development of Russian law in this area:

1) 1973-1990: at this stage, the goal of legal regulation was to create favorable conditions for scientific research in the field of biotechnology and reduce technological risks in the laboratory;

2) 1990-2000: the beginning of lawmaking means that safety standards are being developed for introducing genetically modified organisms into the environment and using them as food products, commercial aspects of using agricultural biotechnologies, and clinical introduction of biomedical technologies are being regulated;

3) from 2000 to the present: the legal regulation of public relations caused by the development of new technologies, their compatibility, as well as gaps that have emerged in recent years due to the lack of legal regulation in the biotechnological sphere[4].

[3] O. V. Romanovskaya y O. V. Bezrukova, “Pravotvorcheskaya politika v oblasti biomeditsiny”, Vektor nauki TGU. Seriya Yuridicheskie nauki Vol: 3 num 18 (2014): 30.

[4] L. N. Vasileva, Biotekhnologii i fundamentalnye prava cheloveka: vektory I predely pravovogo regulirovaniya. Pravo v epokhu biotekhnologii: sbornik materialov studencheskoi konferentsii. (Moscow: The Institute of Legislation and Comparative Law under the Government of the Russian Federation, 2018), 25.

It is obvious to modern lawyers that the regulation of the relevant relations is due to archaism, fragmentation, and presence of gaps and that it requires radical harmonization.

Currently, in Russia, there are only a few legislative acts concerning the regulation of public relations related to processes in the field of biomedicine, in particular, gene diagnostics, namely:

- Federal Law No. 86-FZ "On State Regulation in the Field of Genetic Engineering" dated 05.07.1996 which governs relations in the field of nature management and environmental protection, while the procedure for carrying out genetic engineering using such methods to tissues and cells in the composition of the human body is not subject to its regulation. Only in 2000, an addition to the law except for gene diagnostics and gene therapy was made. Moreover, the said law in Article 2 defines the concept of gene therapy as a combination of genetic engineering (biotechnological methods) and medical methods aimed at introducing changes in the genetic apparatus of human somatic cells to treat diseases;

- Federal Law No. 242-FZ "On State Genomic Registration in the Russian Federation" dated 03.12.2008 which sets the purpose of its regulation to establish a person's identity;

The recently adopted Federal Law No. 180-FZ "On Biomedical Cellular Products" dated June 23, 2016, defines the existing legal mechanisms for regulating the circulation of medicines concerning biomedical cellular products intended for the prevention, diagnosis, and treatment of diseases or conditions of the patient, preserving pregnancy and medical rehabilitation of the patient. Outside the scope of this law, relations remained that arise in the development and production of medicines and medical devices, donation of human organs and tissues, blood and its components when human reproductive cells are used to use assisted reproductive technologies, relations arising from the circulation of human cells and tissues for scientific and educational purposes.

Results and discussion

In this article, we would like to dwell in more detail on issues of genome research in the framework of genetic diagnostics, such as testing and consultation, which are certainly used in medical activities.

To avoid the danger of creating mutated organisms as a result of interference with the human genome, the Oviedo Convention on Human Rights and Biomedicine (1997) states that genetic research is possible only for medical purposes: for preventive, diagnostic, and therapeutic purposes and only if it is not intended to change the genome of the heirs of a given person.

Article 2 of the Federal Law No. 86-FZ "On State Regulation in the Field of Genetic Engineering" dated 05.07.1996 stipulates that genetic diagnostics are a set of methods for detecting changes in the structure of the genome. Genetic testing refers to the testing of a subject for certain features of its genetic system. The bottom line is that in this way one can get some information about a person's predisposition to certain diseases. Such information can be used in two ways. On the one hand, it is necessary to adjust human behavior to

reduce the risk of disease. On the other hand, information on genetic predisposition can be used for discriminatory purposes, including by employers and insurance companies[5].

It is worth noting that in this case, it is necessary to fear the disclosure of confidential information about biomedical data (DNA data) since the unlawful use of such information can serve as grounds for the emergence of large-scale litigation.

Thus, in the light of the jurisprudence of the European Court of Human Rights, the case of Gillberg v. Sweden (Grand Chamber) was examined (Decree of 04/03/2012, complaint No. 41723/06)[6] for criminalizing a university professor for refusing to publish research results. The applicant, professor and head of the Department of Child and Adolescent Psychiatry at the University of Gothenburg was the head of a long-term research project on the study of attention deficit disorder and hyperreactivity in children. The University's Ethics Committee agreed to carry out that project, provided that information about the participants would be available exclusively to the professor and his staff, while the applicant provided a guarantee of absolute confidentiality to patients and their parents. In 2002, the professor refused to provide access to information to a sociologist and a pediatrician. Both researchers filed a lawsuit, which resolved the case in their favor. Having learned about the court's decision regarding the immediate access of researchers to project information, the faculty refused to provide it and later destroyed it. The professor, the rector of the university, and other involved employees were found guilty of misconduct and convicted.

The European Court of Human Rights, examining the professor's complaint about a violation of his rights established by Art. Art. 8.10 of the Convention for the Protection of Human Rights and Dignity of the Person in Connection with the Application of Biology and Medicine (Oviedo, 1997), determined that there were no violations of the provisions of the Convention, indicating that the applicant was not an attending physician for the children involved in the project nor their psychiatrist and that he did not represent children or their parents.

At the same time, the European Court found that the situation of the applicant could not be compared with the situation of a journalist defending their sources of information or a lawyer bound by obligations to the principal. Since the research materials belonged to the university, the European Court concluded that this information was in the public domain.

Thus, genetic diagnostics is a type of testing in which it is impossible to determine a person’s DNA without testing it, that is, it is a person’s test for those or other features of the genetic system.

Article 15 of the Family Code of the Russian Federation slightly extends the boundaries of gene diagnosis, providing for the possibility of medical examination of persons entering into marriage, which also includes counseling on medical and genetic issues. In this case, knowledge about their DNA and the partner's DNA will be informative and will

[5] O. V. Bezrukova y O. V. Romanovskaya, “Pravotvorcheskaya politika v oblasti biomeditsiny v Rossiiskoi Federatsii”, Vektor nauki Tolyattinskogo gosudarstvennogo universiteta num 3 (2014): 28-31

[6] Problemy bioetiki v svete sudebnoi praktiki Evropeiskogo Suda po pravam cheloveka: otchet o provedenii issledovanii, Council of Europe (2016).

enable the couple to predict the DNA of the future children. In Russian legal science, it had been proposed to establish compulsory genetic testing to avoid hiding information about a predisposition to certain diseases. However, to date, the general opinion is that the disclosure of confidential medical information is unacceptable. At the same time, for example, Italian practice allows for, in certain cases, the disclosure of certain aspects of genetic information to close relatives of the patient, even in the absence of the patient's consent to such disclosure[7].

At the same time, while public opinion has been formed about the mandatory genetic testing, by 2025, Russians may have universally available genetic passports. The creation of genetic passports is described in the Presidential Decree "On the Foundations of the State Policy of the Russian Federation in the Field of Chemical and Biological Safety" until 2025 (signed in March 2019). The appearance of such passports should help protect the population from biological and chemical threats, as follows from the foundations of the state biosafety policy approved by the President.

The document has two provisions that relate to the appearance of genetic passports in Russia. First, to monitor chemical and biological risks, it is necessary to create genetic passports for the population, taking into account the legal framework for protecting data on the human genome and to form a genetic profile of the population. Second, it is supposed to create conditions for genetic certification of the population of the development of screening technologies for human, animal, and plant gene pools. The formation of state policy in the area specified in the law will be undertaken by the Security Council, as follows from the document.

However, the law does not explain what exactly is meant by genetic certification and what the genetic passports themselves will be.

We can talk about two types of genetic passports, according to the director of the Genotek Medical Genetic Center, V. Ilyinsky[8]. The first is forensic medicine, which will help to establish a person’s identity, and the second is a more detailed document, which will outline the risks to human health and other features of their body. Such an approach will help make medicine more targeted and personalized, which, ultimately, should help more effectively prevent and treat such diseases.

Currently, the Federal Law on State Genomic Registration in the Russian Federation (No. 242-FZ dated 03.12.2008) is in force, however, its subject is limited to the range of relations that relate to compulsory and voluntary genomic registration for identification purposes. Many countries define this narrow attitude to DNA information in their legislation.

The logical continuation of genetic testing seems to be genetic counseling. However, with the legislative regulation of this issue, it is necessary to determine the procedure for such a procedure, the circle of persons to whom such information is provided. Bioethics also

[7] L. Battistuzzi; R. Ciliberti; F. Forzano y F. De Stefano, “Regulating the communication of genetic risk information: the Italian legal approach to questions of confidentiality and disclosure”, Clinical Genetics Vol: 82 (2012): 205-209 y G. B. Romanovskii, “Konstitutsionnaya pravosub’ektnost’ grazhdan v usloviakh genomnoy meditsiny”, Vestnik Permskogo Universiteta. Juridicheskie Nauki num 37 (2017): 260-271.

[8] U Rossiyan mogut poyavitsya geneticheskie pasporta. April 9, 2019. Retrieved from: https://www.rbc.ru/society/09/04/2019/5ca72ca29a7947fd6d24a96f

comes from the fact that counseling should be voluntary, the information should be provided to the person who applied for testing and no one else[9].

Article 51 of Federal Law No. 323-FZ "On the Basics of Protecting the Health of Citizens in the Russian Federation" determines that every citizen has the right to medical advice for free consultations on family planning, the presence of socially significant diseases and diseases that pose a danger to others, according to medical-psychological aspects of family and marital relations, as well as medical, genetic, and other consultations and examinations in medical organizations of the state healthcare system to anticipate possible hereditary and congenital diseases in one's children. The Family Code of the Russian Federation does not establish additional obligations for counseling, while the circle of persons who are provided with the received information is defined by the code: "the results of the examination of the person entering into marriage are confidential and may be communicated to the person with whom that person intends to enter into marriage, only with the consent of the person who had been examined" (Article 15 of the Family Code of the Russian Federation).

Genetic counseling can cover both adults and children, including infants. Thus, such a technique as a preimplantation genetic diagnosis is actively being introduced, which is carried out with reproductive technologies associated with the artificial insemination of a woman.

During genetic testing of minors, a child may also disagree with such disclosure of their DNA data, since as an adult they will not be able to hide this kind of information due to the parental consent for disclosing it. Besides, according to the results of prenatal genetic testing, termination of pregnancy may be recommended.

At the same time, the right to access to genetic information, including about the origin, is one of the most important in the life of every person. However, it should be noted that in some cases, the disclosure of such information may adversely affect a person, such as a child, in case of adoption. For this reason, it is necessary to observe the principle of balancing the interests of various individuals: biological parents, relatives, surrogate mothers, adoptive parents, a child who wants to receive such information. The right to know one's biological origin was first expressed in the 1989 UN Convention on the Rights of the Child, where article 7 enshrines the right of a child to know their parents from birth. The European Court of Human Rights correlates a child's right to establish legal relations with their biological parents with the right to privacy. This position has been observed by the Court in several cases concerning contesting paternity, conducting DNA tests to determine biological parenthood (judgment of the ECHR dated 11.24.2005, the case "Shofman v. the Russian Federation" (application No. 74826/01)[10], judgment of the ECHR dated 21.06 .2011 in the case of Kruskovic v. Croatia (application No. 46185/08)[11], and others).

[9] I. A. Voronina y E. V. Osinochkina, “Pravovoe regulirovanie v bioetike”, Vestnik OGU Vol: 3 num 164 (2014).

[10] European Court of Human Rights (ECHR) judgment of March 25, 2004, the case of Schoffmann v. Russia (complaint No. 74826/01. Bulletin num 1 (2005).

[11] ECHR judgment of June 21, 2011, in the case of Kruskovic v. Croatia (complaint No. 46185/08). Bulletin num 12 (2011).

Moreover, the right to access information about one's biological origin is not mentioned in the Constitution of the Russian Federation. However, according to some experts in family law, this right can be considered an integral component of the special constitutional legal status of a person[12].

While Article 11 of the Convention on Human Rights and Biomedicine (1997, Oviedo) proclaims that any form of discrimination against a person based on their genetic heritage is prohibited, mass screening of the population, creation of a genetic passport of each citizen will certainly give rise to abuse by credit organizations, insurance companies, and employers. Obtaining information about our DNA will create a large number of judicial precedents, in particular in the field of family relations.

However, one cannot ignore the benefits of such scientific research. Thus, Russia will gradually switch to personalized medicine, which will ensure, among other things, more accurate diagnostics, development of methods for the correction of diseases by cell or tissue engineering, tcreation of animals or cell cultures with a change in the genome that could be used to model human diseases, creation of fundamentally new means of combating drug resistance of pathogens, regulatory support for the use of genetic technologies in biomedicine.

Conclusion

An analysis of Russian legislation on gene technologies shows that it lags behind the regulation of processes in this area by other countries. Even a brief review of the legislation shows that it is necessary to establish at least the minimal restrictions adopted worldwide, such as restrictions on collecting, storing, processing, and using information about human DNA by non-medical organizations; on genetic diagnostics and systematization of information by medical organizations without the corresponding permission of the Government of Russia; on discrimination based on genetic characteristics; on the use of genetic information for other non-medical purposes, except as expressly provided by law.

All of this demonstrates the need to adopt a single special law on state regulation of gene diagnostics and gene therapy, considering, among other things, the provisions pointing to general medical concepts used to regulate this field, principles of respect for human rights in diagnostics and therapy, a ban on the commercial use of genetic material, a ban on forced genetic diagnostics.

To summarize, we can also say that most areas related to biomedical technologies can be legalized only considering ethical and moral aspects.

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