Genetic Ombudsman:
The Need for and Concept of Functioning in terms of New Measures of Legal Freedom

Maksim V. Voronin
Lomonosov Moscow State University, Moscow, Russia

Abstract: The purpose of this article is to describe the need for establishment of the institution entitled “genetic ombudsman” — a new body in the field of human rights protection — in the Russian Federation. The paper addresses the following issues: (1) the role of the ombudsman as an institution acting as a guarantor of democratic freedoms and the value of human life; (2) historical development and the process of becoming the ombudsman; (3) the need to create the institution of the genetic ombudsman during the era of Industry 4.0 (digital society); (4) factors that influence the society’s demand for the establishment of the aforementioned institution; (5) the main goals and objectives of the genetic ombudsman (legal, economic, medical). This research allowed for the possibility not only to highlight the importance of the genetic ombudsman in the context of the political and legal reality but also to identify existing gaps in the normative regulation. In this article, based on the key provisions of the theory of competence, the author attempted to conceptualize the activities of the genetic ombudsman, describe characteristics of this institution, and summarize areas for further research. In the course of this study, logical, comparative legal and formal methods were used.

Keywords: genetic ombudsman; genetic education; actors; information; Industry 4.0; digital transformation; genomic technologies; freedom; interdisciplinarity

Acknowledgements: Supported by the Russian Ministry of Science and Higher Education (Topic: Legal Regulation of Accelerated Development of Genetic Technologies: Research and Methodology Framework; No 730000Ф.99.1.БВ16АА02001).

Contents

I. Introduction ......................................................... 100
II. The Need for “Genetic Ombudsman” ........................................ 101
III. Development of the Ombudsman Institute: Specialization Trend ............. 102
IV. The Concept of Genetic Ombudsman Functions ............................... 108
   IV.1. Factors that Contribute to the Need for Genetic Ombudsman .......... 109
   IV.2. What Goals does the Genetic Ombudsman Have ......................... 111
V. The Comprehension of Genetic Ombudsman Work: Conclusion of the Article and an Intermediate Conclusion for the Development of the Basics of Functioning . . 115
VI. Conclusion .......................................................... 116
References .............................................................. 117

I. Introduction

Nowadays legal reality takes the route of forming interdisciplinary development. This process challenges not only jurisprudence but also legal practice. It is all connected with the nature of the legal matter itself: the law is supposed to be the regulator of social relations, the beginning of civil society development.

People’s lives become more complicated, new social institutions appear, people begin to study the environment and affect it like never before. There is a need to obtain special knowledge for the implementation of previously unknown types of human activities. This will affect the behavior regulators.

“The change of social guiding line system and needs determined the necessity of respective changes in all aspects of social life. The law, which role in society’s life is rising, also changes. Reflecting the urgent social needs, the law, on the one hand, is forced to ‘adapt’ to the changes taking place, and on the other hand, it itself acts as a tool through which the necessary transformations can be carried out most quickly and efficiently” (Rasheva and Gomonov, 2006).
Due to modern trends, the scope of legal regulation is constantly expanding thus covering more and more different spheres of human life. These general theoretical provisions are shifted to questions concerning legal activity, the problem of human rights protection and the specialization of lawyers.

II. The Need for “Genetic Ombudsman”

Previously a cycle of works linked to questions of genetic and legal education has been written. The first article revealed the measure of freedom of the subject of law determining the mode of data use as in the case of genetic information (Voronin, 2019); the second dealt with the measure of freedom of the subject-addressee of genetic education in the context of its content (Voronin, 2020); the third analyzed the work of genetic and legal education executors and how the success and effectiveness of genetic and legal education directly depends on its executors and those having the particular knowledge in the respective field (Voronin and Sakhipgareeva, 2021).

On November 18th, 2021, a round table on the topic “Genetics and Law: The Challenge of the Time 2020–2030” was held at Kutafin Moscow State Law University (MSAL), organized by the Chamber of Young Legislators under the Federation Council with the participation of the expert community of the country’s leading universities (The Chamber of Young Legislators under the Federation Council, 2021). The author of this paper performed as a moderator of this event.

The senator, the first deputy of the chairman of Federation Council of the Russian Federation Committee of social politics, coordinator of Chamber of Young Legislators of the Russian Federation Alexander Varfolomeev, addressing the participants, said that “in today’s work we have to account the possibility of developing the concept of genetic and law awareness and education of the public, creating the institute of ‘genetic ombudsman’ in our country” REC Digital Education, (2021).

Thus, given the previous publications and the recommendations formulated during the roundtable discussion the author aims at conceptualizing the function of a genetic ombudsman.
III. Development of the Ombudsman Institute: Specialization Trend

Over several decades, the ombudsman institute has taken a special place in the life of the country and society. By becoming an inseparable part of democracy, it plays an important role in the evolution of law culture and solidifying legal consciousness among public.

The importance of such a profession is shown in effective and timely protection and advocacy of people, whose rights and interests were infringed and violated.

A significant factor influencing the strengthening of the law and order and the formation of well-being is the presence of such a body in the country.

The history of the ombudsman institution originates in Sweden during the absolute monarchy. At the very beginning of the development of the institution, its duties were mostly limited to monitoring the activities of the judicial institutions, whose actions subsequently had to be reported to the King. However, gradually the powers of the ombudsman began to expand and very soon began to extend not only to the judicial power, but also to the executive power such as the administration of the king. 1809 became the turning point in history of Sweden, when the ombudsman left the king’s service and became under Sweden parliament — Riksdag control. From that moment on, he was obliged to submit an annual report on his work on monitoring the administration, justice, as well as religious organizations (Gil-Robles, 2004).

It is necessary to address the fact that two positions were formed at that time: 1) the Chancellor of Justice, who remained under the jurisdiction of the King and was listed as a public official; 2) the ombudsman of Justice, accountable to the body that elected him, but at the same time independent in carrying out his activities. Later, in the second half of the twentieth century, in connection with the development of the economy, social and spiritual spheres, it was decided to differentiate the ombudsmen by type of activity: for example, one is responsible for social issues; the second solves issues in the field of finance, etc.
The next important stage in the dissemination of the ombudsman institution is the two world wars of the twentieth century. After their conclusion, people realized that a real democracy could be built only if the priority of human rights prevails over state interests. In turn, to achieve this the government must provide a full and stable system of containments and guarantees, under which the population will be able to feel stability and security.

However, the correlation and differentiation of public and private interests is always a difficult task. Another French writer Claude Adrien Helvetius wrote that “interest is a powerful and universal incentive that moves people, luring them to vice, then to virtue” (Protopopova, 2008).

In order to maintain a balance between private and public interests, law and order in the world, and peaceful settlement of disputes, society and the state need impartial and independent mediators who are always able to resolve the conflict, to come to the aid of those whose rights are infringed. A person who could take on such duties and responsibilities is the ombudsmen. The meaning of his work is to protect the helpless and support those in need while carrying out their duties, they should be guided not by greedy and selfish motives, but by compassion and love.

Regardless of the variety of names, the essence and directions of such work is brought to the maintaining of law and order, supervision of government agencies actions and human rights protection.

Therefore, turning to history, one can see that the expansion of the institution of ombudsman is primarily “a response to the request of society, which needs to increase guarantees of human and civil rights and freedoms and new tools for their implementation in the living space” (Council of Europe. Protection, Promotion and Development of the Ombudsman Institution, 2020, p. 10).

At the same time, it is interesting to note the experience of French-speaking Canada. According to Professor Garant from the Laval University of Quebec, people of this province have never really felt an urgent need for an ombudsman, and only since 1966, when the party came to power, promising to establish this institution in its program. And gradually climate for its emergence began to change to be more favorable (Gil-Robles, 2004).
Today, in most countries of the world, there is an ombudsman institution or its analogues. Depending on the historical past, linguistic differences, traditions, etc., this position may be called differently: Commissioner for Human Rights (Russia), European Commissioner for Human Rights (European Union), Commissioner for Human Rights of the Republic of Azerbaijan (Azerbaijan), etc.

Despite the large number of administrative and judicial bodies, whose job is to promptly resolve conflicts, many people still feel oppressed and defenseless. Due to the fact of limited funds, long hearing time of the case or simply the lack of knowledge of certain means of protection, many people do not want to start lengthy, sometimes devastating litigation, so in the process of human evolution the ombudsman institute was developed as one of the methods of protecting their own rights. At this moment, this institute is an effective indicator of government’s system of human rights protection.


In regards to the position of the Commissioner for Human Rights in the Russian Federation, the Constitutional Court of the Russian Federation also expressed its position: “The Commissioner for Human Rights in the Russian Federation is a constitutional body established to ensure guarantees of state protection of citizens’ rights and freedoms, their observance and respect by state bodies, local self-government bodies and officials.”

Similar opinion has been expressed by the Supreme Court of the Russian Federation: “...as follows from the provisions of law, the Commissioner for Human Rights in the Russian Federation and his working staff are a state body established to ensure guarantees of state protection of citizens’ rights and freedoms, their observance and respect by state bodies, local self-government bodies and officials. The

Commissioner is independent and unaccountable to any state bodies and officials in the exercise of his powers.”

It is also important to notice a Federal Law No. 48-FL of 18.03.2020 in the source system “On Human Rights commissioners in constituent entities of the Russian Federation,” which aimed at ensuring and fulfilling human and citizen rights on federal and regional level.

In addition, it is important to draw attention to the fact that in Russia there are ombudsmen in other areas other than the Commissioner for Human Rights:

1) President's commissioner for the protection of entrepreneurs’ rights in Russian Federation (Federal Law No 78-FL of 07.05.2013 “On Commissioner for the Protection of Entrepreneurs’ Rights in the Russian Federation”);

2) Commissioner for the rights of consumers of financial services (Federal Law No 123-FL of 04.06.2018 “On Commissioner for the Rights of Consumers of Financial Services”);


4) In 2013 the President voiced the idea of creation the position for commissioner for the rights of physically challenged.

Considering the digital transformation of society and the problems of such transformation, it is important to notice the work of digital ombudsman, whose societal institution was established in 2021. For example, if a person faced cyberbullying, fakes or lost their personal data in results of criminal activity, they will have the ability to contact digital ombudsman and their team for help.

---


3 Experts assessed the necessity of the ombudsman for physically challenged people in Russian Federation. Available at: https://ria.ru/20130329/929979230.html [Accessed 15.01.2022] (In Russ.).

4 See: Youth digital ombudsman — the first digital protector of Russian youth. Available at: https://youthombudsman.ru/ [Accessed 11.01.2022] (In Russ.).

These institutions were not formed for the sake of complicating the bureaucratic system of the state and additional difficulties. The need for the ombudsmen in these areas was associated with the current agenda of the time and the challenges of society.

For example, due to difficult economic situation in the country, the post of the President’s commissioner for the protection of entrepreneurs’ rights was established to overcome administrative barriers and the pressure of unqualified state employees and corruption offenses.

As an example, illustrating the “narrow” functions of the ombudsman, we can refer to foreign experience, in particular German. Article 45-b of the Basic Law of the Federal Republic of Germany establishes: “For the protection of fundamental rights, the Bundestag commissioner of defense is appointed as an auxiliary body of the Bundestag in the exercise of parliamentary control. Details are regulated by federal law.”

The main task of the military ombudsman in Germany is the protection of military personnel who are as full and full-fledged citizens of their country as ordinary residents. As part of the job, the commissioner of defenses of the Bundestag has the right to demand from the Federal Ministry of Defense, as well as from other official authorities, to inform him and provide information and opportunity to study the case materials at any time. In addition, the German military ombudsman has the right to visit any unit of the Bundeswehr (armed forces of the Federal Republic of Germany) at any time without prior notification.

“Among the specialized ombudsmen the Health Ombudsmen (in the UK at the level of England, Wales, Scotland and in the USA); ombudsmen for the supervision of correctional institutions (in the USA in Minnesota); prison ombudsmen (in the states of Oregon, Alaska, Hawaii, Iowa, Nebraska, Connecticut, Maryland, New Jersey, New York, Ohio, South Carolina, Wisconsin, Michigan in the USA) should be named” (Trifonov, 2020, p. 119).

---


7 See: Commissioner for Military Affairs. Available at: https://www.bundestag.de/resource/blob/582058/761c6bcad25367ddaca07a33d3e167aa/flyer_wehrbeauftragter_ru-data.pdf [Accessed 11.01.2022].
Today the society actively begins to live in Industry 4.0 era. As a result, the humanity will be faced with new challenges and threats. The characteristic of 21st century can be described as such: the increase of amount of information (BigData; the volume of data is rising in geometrical progression), the development of molecular chemistry and bio nanotechnology, general digital transformation, and the increase of interdisciplinary knowledge relevancy.

This approaching era is the time of large-scale opportunities and equally significant threats. It will be the world where interaction between virtual and physical systems will be a common thing. All crucial changes in economy, technological and social spheres during forth industrial revolution will lead to necessary changes of the system of law.

Advancing changes of law is not a want, but a necessity since there are growing numbers of new unregulated social relations. In general, one can speak about transformation of the measure of freedom of juridical entity, but generalization of this process on general theoretic level is still needed to be done. And the problem that is being examined is one of the most important sections of such transformation linked to digitalization of social and humanitarian knowledge and its use. In fact, the need in digital and genetic ombudsmen is a new measuring law practice empiricism. During the creation of such institutions, the competences and place of this structure in the system of social relations will be expected to be defined.

Within the framework of genetic progress “one of the new socio-legal receiving institutional registration in the legal system is genetic data and personal genetic information, about genetically modified organisms. At the same time, the problem itself is not new. The freedom of genetic scientists in the field of scientific knowledge has been closely monitored by the state and society for more than 80 years. But in the conditions of the new reality, this freedom began to acquire a kind of ‘individual immersion’” (Voronin, 2020, p. 16).

Legal regulation often lags behind the rapid evolution of science and technology, resulting in many gaps and conflicts in law that cannot be resolved in a timely manner.

In part, this process is somewhat natural, but it acquires new accents in a changing world. Thus, law is always directed at social relations, which in general are the basis of the system of law itself; in
many ways, both the content and the structure of law are determined by the state-power will and the legal policy that specifies it (Voronin, 2016, p. 119). What is important here is that the content of public relations is changing, previously humanity did not know such a large amount of information about the health of a particular person, it was impossible to carry out genetic correction and therapy, to influence other important spheres of life; there is a new emphasis between the private and public in human activity. Quite a lot of examples can be given based on the analysis of information about the development of society and the state in the context of the COVID-19 pandemic (Sinyukov and Mokhov, 2021).

“In the USSR, there was no legal regulation of genetic research, and there was no uniform measure of law in relation to problems of genetic nature, in modern Russia they have not developed up to now either, and therefore the most important is the conventional regulation of the institute of genetic research, as well as sectoral regulation at the domestic level” (Voronin, 2019).

Since humanity is not yet ready to fully enter the new era, the state will have to find solutions to problems and create all conditions for the transition between eras to be painless for the population and law and order to be preserved.

IV. The Concept of Genetic Ombudsman Functions

The following paragraph offers the concept of genetic ombudsman to improve legal system in Russia and to reduce risks and negative consequences.

To prove the need of establishing the role of special advocate one would like to focus on the following parts of analysis of the institute that is being studied:

1. factors that influence the need of creation of genetic ombudsman institution;
2. the purposes of genetic ombudsmen and problems that they solve;
3. genetic ombudsman as the main executor and guarantee of genetic and legal education;
4. genetic ombudsman or effective advocate for violated human rights.
IV.1. Factors that Contribute to the Need for Genetic Ombudsman

Even though heredity discussions were conducted earlier, the first research of biological patterns that determine the translation of features from parents to offsprings were conducted by Gregor Mendel in the Czech Republic in the 19th century (Agafonov, Belousov and Vypkhanova, 2022, p. 9).

More than one hundred years later genetic science has made an impressive leap forward. Nowadays scientists discuss the possibility of diagnosing predisposition to genetic illnesses.

“The changes in legal regulation of public relationships are dictated by their own development in different areas of life. The legal regulation of genetic research is the problem that was defined not to appeal to legal volition. This problem is faced due to scientific and medical progress” (Voronin, 2019).

At this time parents can have the screening made for genetic abnormalities which can be transferred to the offspring. This procedure allows future parents to prepare themselves for future challenges and avoid any negative consequences in time. Without a doubt these results in biotechnology sphere can cause not only society’s approval but also suspicions and fears.

On November 17th, 2021 the President of the Russian Federation held a meeting in relation to genetic technology development in Russia. During this meeting its participants examined the process of carrying out the federal scientific program for genetic technologies development until 2027. They also discussed financial support of research in genetic sphere, methods of drawing in economic sector into genetic technology development in agriculture, medicine, and industrial microbiology.

During the event, the Head of the State emphasized that “it is necessary to clearly define the limits of permissible use of genetic technologies. We are talking not only about modern legal regulation, but also about compliance with ethical standards: they must be understood and recognized by researchers and businesses and, crucially, accepted by society, enjoy the trust of people. Of course, the most important topic is genetic information, and first we need legislative mechanisms
that will ensure the rights of citizens, regulate the issues of obtaining, using, and protecting genetic data of a person and his family, including future generations.”

And now, the country has clearly formed a request to notify the population and familiarize them with the progress in the field of biotechnological industries, as this directly affects us and our loved ones.

It is worth recalling the case of the Chinese scientist Jiankui Xe. He was sentenced to three years in prison and a fine of 3 million yuan (about 430 thousand dollars) for an illegal experiment with the birth of twins from genetically modified embryos. Violating ethical norms and relying only on their own feelings, the doctor has conducted experiments on the embryos and mislead the patients. The procedure was unacceptable because the subjects believed that it was carried out legally. However, it turned out that all the documents confirming the alleged legality of the experiments turned out to be a fake. This indicates the need to create a legislative material that would act as a reliable regulator of such legal relations. However, the urgency of the issue lies in the need to create legal material based on which people’s rights will be ensured and in ways of informing people about it.

During the creation of legal materials, the legislator must pay attention to the fact that most people live in the state of limited and imperfect possession of information. Legal regulation often cannot achieve its purposes because of that. The reason is that most of affected people would not see any effects. It is important that socially important information that influences people’s behavior was effective and achieved its goals for the good for society. The rapid growth of social media platforms and emergence of new channels of information that are less transparent and obvious compete with traditional official forms of information distribution.

---


9 Chinese scientist was sentenced to 3 years in prison for creating the genetically modified children. Available at: https://tass.ru/proisshestviya/7445829 [Accessed 15.01.2022] (In Russ.).
To overcome the phenomenon of limited possession of information the combined use of official and unofficial channels is needed. It is logical to divide information distribution about genetics into two types: official (governmental facilities) and unofficial (social media content creators).

With all of this going on, a genetic ombudsman will manage both channels as one entity. Thus, it would be possible to achieve the principle of objective truth, independence, and protection of human rights as much as possible since the main mission of the genetic ombudsman is to represent and protect the interests of the population.

IV.2. What Goals does the Genetic Ombudsman Have

The protection of genetic data. As stated earlier one of the primary goals of genetic ombudsman is their duty of protecting the genetic data of a human.

Today biomedical research makes it possible to diagnose diseases at an early stage and to carry out timely prevention. However, most people are afraid that the results of the tests that they have done in the doctor’s office may be used later for illegal purposes.

It is not a secret that genetic information allows the doctors to learn a lot about a patient, but it also provides data about the family and genealogy. The possession of such knowledge can lead to fraudulent crimes and invasion of privacy.

Genetic certification, the formation of a large database of genes and conduction of experiments raises doubts in society about their future safety. Soon there may be a problem in the fields of insurance and lending. People will be discriminated against based on their health status.

For example, “in Estonia, in 2000, in order to protect individuals from discrimination, insurers were prohibited from collecting genetic data about insured people and individuals applying for insurance. Insurance agencies were prohibited to require the clients to provide tissue samples or DNA descriptions. It was banned to establish different insurance conditions for individuals with different genetic risks and develop preferential rates and to restrict the definition of insurance cases” (Suvorova, 2019).
However, of particular concern is the fact that a unified legal concept of genetic information has not yet been formed in Russia, its legal status has not been determined. Despite the large number of opinions and points of view on this matter, lawyers, doctors and other specialists have not formed a common position on this issue.

Thus, one of the main tasks of the genetic ombudsman and his team will be to determine the legal status of genetic data, as well as its boundaries.

**Jurisdiction purposes.** It has long been no secret that for the last thirty or forty years, criminologists and law enforcement agencies have been actively using genetic fingerprinting in the exercise of their functions for a long time.

During this time, DNA data banks have been formed in different countries, which contribute to the investigation of crimes: Fichier National Automatise des Empreintes Genetiques (FNAEG) in France; The National DNA Database (NDNAD) in the UK; Combined DNA Index System (CODIS) in the US.

A similar system exists in Russia. According to Federal Law No 242-FL of 03.12.2008 “On State Genomic Registration in the Russian Federation,” a federal database of genomic information (FBoGI) was created in 2009 in our country. This repository contains genomic information obtained due to mandatory and voluntary state genomic registration.

In accordance with article 3 of the said Law, the following people are subject to mandatory state genomic registration: 1) convicted and serving a sentence of imprisonment for committing grave or especially grave crimes, as well as all categories of crimes against sexual integrity and sexual freedom of the individual; 2) unidentified people whose biological material was seized during investigative actions; 3) unidentified corpses.

Voluntary registration is carried out in accordance with the procedure separately established by law based on a person’s written will.

The main problem in conducting such examination is the issue of storing unique genetic data. What should the authorities do if, after taking tests, it turns out that people were not involved in a crime? Let’s
turn to the case of “S. and Marper v. the United Kingdom,”\textsuperscript{10} considered by the European Court of Human Rights. The essence of the dispute was that the minor applicants, who had not been convicted, asked the police to remove their DNA samples and fingerprints from the database. However, neither the police nor the judicial authorities agreed to satisfy their demands, referring to the fact that: 1) such materials were in limited access; 2) an expanded database provides huge advantages in the fight against crime.

After considering the dispute, the Court came to the following conclusion: “the comprehensive nature of the right of retention applied in the applicants’ case violated the fair balance of competing public and personal interests, and in this respect the respondent State went beyond the acceptable limits of discretion. That means that the storage of personal data constituted a disproportionate interference with the applicants’ right to respect for their privacy and could not be considered necessary in a democratic society.”\textsuperscript{11}

Thus, given the special importance of public relations regulated by criminal law, the constant search for a balance between private and public interests, the task of establishing public order, it is necessary that such relations be under additional and enhanced supervision of a person who not only has the necessary knowledge for this, but also has the appropriate competence.

\textbf{Economic goals.} Today, the use of genetic technologies in the economy has become the main trend that allows you to optimize production, increase productivity and profit. The increase in the population and growth of its needs forces manufacturers to constantly find new ways to create their products. The use and implementation of genetic technologies in industrial biotechnology reveals the possibilities of extracting a large range of chemical substances and biomaterials.


from renewable material, which can significantly improve traditional
production.

In addition, there is a question about the nutrition of the population. Since the amount of fertile land is getting smaller, the soil does not have time to undergo the restoration procedure and get enough of the necessary trace elements, products containing GMOs have entered human life.

The ambiguous attitude towards GMOs has generated a lot of controversy. Rospotrebnadzor has banned the import of products from China that contain genetically modified corn. 12 Despite restrictions, research in this area is still going and now you can often buy goods containing GMOs.

The production and sales of such products is directly related to public and private interests, the balance between which is designed to be established by genetic ombudsman.

Preservation, maintenance, and protection of biological collection. To this day, there are no legislative concepts of bioresource collections or at least biological collections in Russian Federation. There are no special laws dedicated to bioresource collections. There are only separate mentioning in other Federal laws, such as “On the Animal World,” “On Specially Protected Natural Territories,” “On Biomedical Cell Products.” Since it is obvious that the legislative framework is mosaic and incomplete, that creates many problems. There are also acts of ministries and departments, but they regulate only certain issues in this area. The acts of the departments are mostly more technical than legal.

In addition, there are currently no acts defining the status of biological collections. There is a separate question about the use of the current legislation to collections, to biobanks (for example, warehouse storage norms). There is no clear list of organizations that keep those collections, there is no understanding of their jurisdiction. These are museums, zoos, educational organizations and bioresource centers that do this in other countries. In Russia, these are probably collective use

---

12 Russia has banned the import of corn noodles and crisps from China due to GMO in them. Available at: https://www.rbc.ru/rbcfreenews/6163ee8f9a794713ad5df641 [Accessed 15.01.2022] (In Russ.).
centers and unique scientific installations. Their legal status is also not fully defined.

The related issues of customs regulation, the procedure for collecting, accounting, and storing samples, the scope of use of existing biological collections, the replenishment of collections, the procedure for exchanging samples have not been resolved.

It is obvious that Russian Federation needs special legal regulation for bio collections at the level of federal law. The person who will assist the standard-setting activities, monitor the progress of work, and actively contribute to solving this problem should be the genetic ombudsman as the main performer of genetic education and human rights activist.

V. The Comprehension of Genetic Ombudsman Work: Conclusion of the Article and an Intermediate Conclusion for the Development of the Basics of Functioning

All the above make us conceptualize the activities of the genetic ombudsman based on a functional approach. At the same time, it is important to determine the main activities of the genetic ombudsman. From theory of law point of view, it is necessary to pay attention to such issues as its competence (officially/unofficially it may be an element of civil society, the presence of financing apparatus), the limits of discretionary powers and institutional design in general.

Based on the basic elements of the theory of competence, the possible jurisdiction of the genetic ombudsman can also be considered including “a) normative goals; b) subjects of reference as legally defined spheres and objects of influence; c) authority as a guaranteed measure of decision-making and action” (Tikhomirov, 2001).

In this paper, the clusters of issues that the author considers the most urgent for the protection of the genetic ombudsman have been investigated. Here are the key provisions of a possible legally formalized concept of a genetic ombudsman in the Russian Federation.

The main purpose of the genetic ombudsman’s work is to protect human rights in the use of genetic information, the use of biological and genetic technologies, including those related to the decoding and
editing of the human genome, the use of genetic information about a person for jurisdictional, scientific, medical, economic, and other purposes, as well as the protection of social, scientific, medical, and other public institutions associated with these rights.
— Thus, the following issues should be the subjects of such genetic ombudsman:
— The use of genetic information by different subjects of law, legal protection.
— Protection of rights in genetic research, experiments, clinical trials and medical analyses and other medical interventions related to the invasion of the human genome.
— Issues of legality and safety of the use of products, raw materials and other goods obtained using genetic technologies.
— Assistance in the protection of human rights, the implementation of jurisdictional activities, including matters of the legality of genetic examinations.
— Protection of people suffering from genetic diseases, including the security of specialized medical care and medicines.
— Issues of genetic legal education, and cooperation within the framework of protectionism of genetic human rights.

VI. Conclusion

The paper considered the needs of introducing the institution of genetic ombudsman, the main stages of formation and preconditions for the narrowly focused specialization of such a human rights advocate, the basic conceptual provisions that are important for its introduction into political and legal reality were outlined.

The complexity of the detailed regulation of genetic ombudsman is associated with the still emerging regulatory material, the so-called “Lex genetic” field. This further intensifies the need to accelerate the development and adoption of the concept of genetic ombudsman, as well as to strengthen the educational component in this matter. In the subsequent work, it is planned to investigate a possible interdisciplinary
educational standard of abilities for such human rights advocate, which is largely associated with the introduction of certain qualification requirements for the future genetic ombudsman.

References


Information about the Author

Maksim V. Voronin, Cand. Sci. (Law), Associate Professor, Lomonosov Moscow State University, Moscow, Russia
1 stroenie 13 Leninskie Gory, Moscow 119991, Russia
maksim.v.voronin@mail.ru
ORCID: 0000-0002-4129-2682