

Dr. Nevena Petrušić*

NORMATIVE FRAMEWORK FOR THE PROTECTION AGAINST GENETIC DISCRIMINATION IN SERBIA

The paper is devoted to a normative framework of protection against genetic discrimination in the legal system of the Republic of Serbia, contained in the Law on Patients Rights, as of 2013 and in the Law on Prevention and diagnostics of genetic disorders, genetically conditioned anomalies and rare diseases, as of 2015. The analysis has shown that the rules on protection of the genetic data and the use of genetic samples, which are crucially important for prevention of genetic discrimination, have not been harmonized with contemporary ethical and legal standards. The contents of the Article 9 of the Law on Prevention and diagnostics of genetic disorders, genetically conditioned anomalies and rare diseases reduces the scope and level of protection against genetic discrimination in relation to the protection, given by the General Antidiscrimination Law. The legal definition of the genetic discrimination notion is not comprehensive, clear or precise, either, so it causes confusions, which, additionally, make the application of anti-discrimination regulations more difficult. Having in mind the harmful effects caused by the genetic discrimination, there is a need to eliminate the observed normative failures in due time and enable people to enjoy the benefits, provided by genetic investigations, without the fear from discrimination. In order to prevent the genetic discrimination, it is necessary to work on both information providing and raising awareness about the genetic privacy and the genetic discrimination problem, but also on promotion of the social justice and development of sensibility for bioethical challenges brought by the new age.

Key words: *Genetic privacy. – Genetic features. – Protection against genetic discrimination.*

* Professor, University of Niš Faculty of Law, nevena.petrusic@gmail.com. The paper is the result of research in the Project: “Harmonization of Serbian Law with the European Union Law”, financed by the University of Niš School of Law in the period 2013–2018.

1. HUMAN GENETICS AND THE NON-DISCRIMINATION RIGHT – THE KEY ACHIEVEMENTS AND CHALLENGES

Unbelievable expansion of medical genetics which followed after the human genome decoding¹ enabled discovery of thousands of genetic diseases and disorders through genetic testing, and owing to findings in the field of genetic epidemiology and pharmacogenomics, the medical science greatly advances towards the personalized medicine, which should ensure individualized medical treatment of patients in accordance with their genetic profile.

New possibilities offered by genetic technologies initiated huge bioethical debates and opened a series of ethic dilemmas which required urgent solutions in order to establish clear limits of their applications and protect the essential human values. Among the problems which required a quick normative reaction, the problem of genetic discrimination² occupied a significant place. Namely, the comprehensive genetic screenings enabled establishing of genetic variability among the members of certain groups, but that created the possibility of the racism ideology justification, and additionally, stimulation of the race and ethnic discrimination by the non-scientific interpretations of differences in the inheritance material of some races and ethnic groups.³ On the other hand, genetic testing opened the space for, not only genetic privacy invasion, but also for discrimination of individual persons based on their genetic characteristics.

Numerous researches in America, Australia, Canada and EU have shown that in the countries in which genetic tests are largely available, the genetic discrimination is in expansion, and that it is increasing in parallel with the increase of the number of genetic tests⁴ and that it is most

¹ Human genome mapping is the result of the megaproject “Human genome” work, the biggest and the most expensive scientific venture of all times, started in 1989, led by James Watson. See: Wolfram Henn, Eckart Messe, *Human Genetics* (translation), Laguna, Beograd 2011, 8–15, and the literature, mentioned there.

² The appearance of genetic discrimination threatened to endanger the “Human Genome” project goals realization. Due to that, Francis Collins, the Director of the Human Genome National Institute, recommended a strict protection against genetic discrimination. See: *Introductory remarks on measure*, Congressional Record—Senate, 846.

³ On the global level, the superiority doctrine based on the race difference was pronounced a non-scientific and false, already far back in 1995, pointing to the fact that it was morally unacceptable and socially unjust and dangerous, therefore it cannot be justified either in theory or practice. See the Preamble of the International Convention on the Abolition of all Forms of Race Discrimination.

⁴ Confirmed in researches conducted in America, Australia, Canada and United Kingdom, far back in 90’s of the last century. More: Sandra Taylor, Sue Treloar, Kristine Barlow-Stewart, Margaret Otlowski, Mark Stranger, “Investigating Genetic Discrimination in Australia: Perceptions and Experiences of Clinical Genetics Service Clients Regarding Coercion to Test, Insurance and Employment”, *Australian Journal of Emerging*

spread in the fields, vitally important for people: in the social insurance and in the fields of labour and employment. In the field of insurance, genetic discrimination is most frequently reflected in insurance rejection or in the insurance premium increase based on the data on an individual person genetic predispositions, that is, his/her family members, and in the fields of work and employment, it is most frequently done by employment rejection and dismissal from work or denying of employees advancement, based on their genetic profile data.⁵

The fear from discrimination and stigmatization has caused mass rejection of people to participate in genetic tests and screenings.⁶ Negative effects of such a situation are manifold. Rejection to do the tests results in a missed opportunity of genetic diseases early detection and treatment, that being harmful for those at risk from getting diseases, but for the entire society, as well, because, due to untimely treatment, the health protection costs are increased, and, what is specifically important, the development of new genetic therapies is stagnating, because it is not possible without the inclusion of a big number of individual persons in genetic tests.

Dynamic development of new genetic technologies permanently produces new challenges and controversies and the need for regulations change. The changes are oriented to strict ban of genetic discrimination in

Technologies and Society Vol. 5, No. 2, 2007, 63–83. http://www.researchgate.net/publication/26486253_Investigating_Genetic_Discrimination_in_Australia_Perception_and_Experiences_of_Clinical_Genetics_Services_Clients_Regarding_Coercion_to_Test_Insurance_and_Employment. asp, 17.06.2015.

⁵ See: *Faces of Genetic Discrimination – How Genetic Discrimination Affects Real People*, National Partnership for Women & Families on behalf of the Coalition for Genetic Fairness, 2004. <http://go.nationalpartnership.org/site/DocServer/FacesofGeneticDiscrimination.pdf?docID=971>. asp, 17.06.2015.

⁶ In America, 32% refused to have the free test done for the breast cancer risk, as offered by American National Health Institute, stating that their reason for concern was that they and their daughters would be exposed to discrimination in health insurance. See: *Introductory remarks on measure*, Congressional Record—Senate, January 22, 2007, 846. <http://www.gpo.gov/fdsys/pkg/CREC-2007-01-22/pdf/CREC-2007-01-22-pt1-PgS828-3.pdf>. asp, 17.06.2015. A huge percentage of relatives of persons affected by Huntington's disease refused genetic testing, and even 46.2% of subjects were exposed to discrimination and stigmatization, Cheryl Erwin, Janet K. Williams, Andrew R. Juhl, Michelle Mengeling, James A. Mills, Yvonne Bombard, Michael R. Hayden, Kimberly Quaid, Ira Shoulson, Sandra Taylor, Jane S. Paulsen, *Perception, Experience, and Response to Genetic Discrimination in Huntington Disease: The International RESPOND-HD Study*, http://www.researchgate.net/publication/44597481_PerceptionExperienceand_Response_to_Genetic_Discrimination_in_Huntington_Disease_The_International_RESPOND-HD_Study. asp, 12.06.2015. The situation is also similar in the EU states Beatrice Godard, Sandy Raeburn, Marcus Pembrey, Martin Bobrow, Peter Farndon, Segolene Aymé, “Genetic information and testing in insurance and employment: technical, social and ethical issues”, *European Journal of Human Genetics*, 2003, 11, Suppl. 2, 123–142. <http://www.nature.com/ejhgjournal/v11/n2s/full/5201117a.html>. asp, 17.06.2015.

employment, in that, the genetic monitoring is allowed over the workers, dealing with toxic matters, for the purpose of health protection at their work post. However, when it is to do with insurance, there are still debates, discussing about if and to what extent it is necessary to respect the interest of the insurer to make the risk assessment and based on that, to decide about the insurance, having in mind that based on the results of genetic testing, in most cases it is not possible to give a reliable prognosis in view of the disease development and the expected length of life. The key argument of the authority is that the genetic data must remain confidential and be used only for medical purposes, and that in the field of insurance, as well, individual persons must not be discriminated on the grounds of their genetic characteristics. The insurers, however, assert that it is not to do with discrimination, but with legitimate differentiation, of not the individuals only, but of different risk categories, as well and that the entire insurance system is based on the just and reciprocity principles, in which the premium amount, naturally must be based on the risk.⁷ The future will show the direction of further development of legal protection against genetic discrimination. It is certain, however, that it will be one of the most dynamic fields of antidiscrimination law.

Although there are no exact data on the genetic discrimination prevalence in Serbia, it may be concluded, having in mind other countries experience, that it is not a far future in Serbia either, for it has already been manifested and it will be increasing along with the increased number of people included in genetic tests, and these are also increasing,⁸ in spite of the lack of financial resources for costly equipment and consumables procurement, and in spite of scattered research personnel and other difficulties.⁹ In parallel with it, there is the increased application of commercial diagnostic, presymptomatic and predictive genetic tests, financed from public and private sources, respectively. The increase of a number of individual persons, included in genetic tests widens the space for genetic discrimination, and in order it would not take roots, it is necessary to take the comprehensive and coordinated measures in due time, to prevent its manifestations and enable people to enjoy the benefits offered by genetic tests without the fear from discrimination.

⁷ Godard, B. Raeburn, S. Pembrey, M. Bobrow, M. Farndon, P. Aymé, S. “Genetic information and testing in insurance and employment: technical, social and ethical issues”, *European Journal of Human Genetics*, 2003, 11, Suppl. 2, pp. 123–142.

⁸ Data about that are available at the web site of Serbian Geneticists Society, within the section Medical genetics. <http://www.dgsgenetika.org.rs/sekcije-medicinska-genetika.ph.asp>, 15.06.2015.

⁹ The Republic of Serbia Strategy of Scientific and Technological Development for the period 2010–2015, also contributed to that, by which the bio-researches, particularly in the field of genetics, have been established as one of seven scientific priorities. See: The Strategy of Scientific and Technological Development of the Republic of Serbia for the period 2010 – 2015, *Official Gazette of RS*, No. 13/2010.

Like in other countries, a comprehensive and coherent normative framework is also a basic precondition for effective prevention of discrimination in Serbia. For that reason, this work is devoted to regulations which, in their entirety, make a domestic normative framework of protection against genetic discrimination. The immediate cause for a topic choice is the adoption of long awaited and eagerly expected *Law on Prevention and Diagnostics of Genetic Diseases, Genetically Caused Anomalies and Rare Diseases* as of 2015.¹⁰ Although this law was named popularly “Zoja’s Law”,¹¹ recognized in public as a law to improve medical treatment of children affected by rare diseases, it has much wider significance because, for the first time in Serbia, it regulates in a comprehensive way, the conditions of genetic testing and mass genetic screenings.¹² That is why it is important for effective prevention of genetic discrimination, as well.

The objective of this work is to make a critical review of the actual situation in this specific field of our national antidiscrimination law, but also to point out to the genetic discrimination problem, which is in Serbia still on the margins of scientific interest. Having in mind that in the domestic literature, the legal concept of genetic discrimination has not been elaborated more specifically, the first part of work considers the concept, manifestations and characteristics of genetic discrimination, the second one gives a short presentation of the international standards and solutions in the Comparative law, while the third part is devoted to analysis of some legal solutions in Serbian legislation, in order to estimate if they provide a satisfactory level of protection against genetic discrimination.

2. GENETIC DISCRIMINATION – NOTION, CHARACTERISTICS

Genetic discrimination is a complex and multifaceted ethical, psychosocial and legal phenomenon. As a legal phenomenon, it has not been

¹⁰ *Official Gazette of R. Serbia*, No. 8/2015 (hereinafter: ZGBARB).

¹¹ Adoption of ZGBARB has been initiated by the parents of a girl, Zoja Mirosavljević, who died from Batten disease. When she was affected, the physicians in Serbia could not establish the diagnosis of her disease, so the parents were referred to ask for solution outside the country. They asked from the Republic Fund of Health Insurance to bear the costs of diagnostics and treatment abroad, but they were refused because Zoja’s disease had not been discovered and therefore, it was not on the list of diseases, the treatment of which might have been covered by the Fund resources. Zoja’s parents managed to travel to London on their own account, where the disease was diagnosed. The adoption of the Law was proposed by the deputy to the Assembly, Dušan Milosavljević, in January 2014, but his proposal did not get the majority, necessary to be put on the Agenda. The Law was adopted one year later, on 23 January 2015.

¹² See: *ZGBARB Proposal Rationale*, <http://www.parlament.gov.rs/upload/archive/files/lat/pdf/predlozizakona/2245-14Lat.pdf>. asp, 17.6.2015.

defined by legal enactments which ban it, therefore, in order to be understood, it is necessary to rely on the definition and elements of the general concept of discrimination.

In the contemporary law, the expression “discrimination” is unjust differentiation or unequal treatment, that is, indulgence toward a person, that is, a group of persons, based on some of their actual or presumed personal feature, such as the race, skin color, nationality/ethnic origin, sex, sexual orientation, genetic particularity, health condition, disability or any other personal feature.¹³ There are two basic forms of discrimination – direct and indirect discrimination, respectively. The direct discrimination occurs when a person (group) is treated unequally (less favorable), because of some personal feature, compared to some other persons (group) in an analogue situation (*comparator*) which do not have such a feature. Indirect discrimination is a form of discrimination which occurs when an apparent neutral rule, criterion or practice produces disproportionately negative effects compared to a person or a group of persons, because of some personal feature of theirs, compared to some other persons, that is a group.

Genetic discrimination is a special kind of discrimination, the key specificity of which is the very ground of discrimination, and it is a genetic characteristic of an individual person – one of personal characteristics which is a part of the integrity and the identity of each individual person. Although in literature one may encounter various definitions of the notion “genetic discrimination”, in spite of differences, authors agree that the essence of genetic discrimination is the less favorable treatment of an individual person on the grounds of his/her actual or presumed enetic characteristics,¹⁴ in that, the data about a genetic characteristic may stem from genetic testing or from the family history.¹⁵

¹³ About the legal notion of discrimination, see: Petrušić, N., Krstić, I., Marinković, T, *Komentar Zakona o zabrani diskriminacije*, Pravosudna akademija, Belgrade, 2014, 20–21.

¹⁴ In the literature of older times, there has been potentiated the difference between genetic characteristics of a discriminated person, that is, the members of his/her family, in relation to the “normal” human genome. The expression “normal human genome” is under quotation marks because, as pointed out, it is not possible to define what a “normal” genome is, having in mind that there are mutations, which are easy to qualify as abnormal genes, but there are also mutations and benign polymorphisms, present in all individuals. See: Paul R. Billings, Joseph S. Alper, Jonathan Beckwith, Carol I. Barash, Marvin R. Natowicz, “Reply to Hook and Lowden: the definition and implications of genetic discrimination”, *American Journal of Human Genetics*, Vol. 51, 1992, 903–905. Stated according to: Marvin R. Natowicz, Jane K. Alper, Joseph S. Alper, “Genetic Discrimination and the Law”, *American Journal of Human Genetics*, Vol. 50, 1992, 465–475.

¹⁵ Larry Gostin, “Genetic discrimination: The use of genetically based diagnostic and prognostic tests by employers and insurers”, *American Journal of Human Genetics*,

Like all other forms of discrimination, genetic discrimination is the consequence of stereotypes and prejudices, the basic cause of which is – ignorance. It is duly followed by stigmatization, which includes names calling, stereotypization, separation and loss of social status, and its basis in the attitude that the social identity of such persons is less valid because they have the “bad blood”¹⁶ and are the carriers of diseases.¹⁷ It causes suffering of individuals, loss of self-respect, alienation from the family members, disturbed family relations, etc.¹⁸

Unequal treatment may be qualified as genetic discrimination only if in time of discriminatory act commitment an individual person has not got the genetic disease symptoms (*asymptomatic individuals*). If the genetic disease, that is, disturbance, has developed, it is to do with discrimination on the basis of health condition or disability.¹⁹ Separating the genetic discrimination into the special category is relatively new, in the first place because in some cases it is difficult to differentiate genetic discrimination from discrimination based on the health condition, that is, disability. It has been realized, however, that difficulties in recognizing genetic discrimination do not negate the need to treat genetic discrimination as a special type of discrimination,²⁰ because in that way, there is provided protection against discrimination to individual persons who, at the time of discrimination, were just at risk of getting diseased, without any certainty that they would get diseased.

As a rule, discrimination is a reaction to some, obviously personal feature of an individual, such as sex, skin colour, disability, etc., while genetic discrimination is specific for genetic profile of an individual which is not obvious, so that making discrimination implies that a discriminator actively searches for genetic data.²¹ One of the specificities

Vol. 17(1–2). 1991, 109–144, <http://scholarship.lawgeorgetown.edu/cgi/viewcontent.cgi?article=1763&context=facpub.asp>, 17.6.2015.

¹⁶ Thomas Lemke, “Beyond genetic discrimination: Problems and perspectives of a contested notion’ Genomics”, *Society & Policy*, Vol. 1, 2005, No. 3. Stated according to: S. Taylor *et al.*, 64–65.

¹⁷ C. Erwin *et al.*, 3.

¹⁸ S. Taylor *et al.*, 65.

¹⁹ It is considered that the victims of genetic discrimination may also be those individuals, affected by some genetic disease, if the cause of discrimination is their genotype, rather than a genotype-based phenotype, which is determined in any individual case. Joseph S. Alper, Marvin R. Natowicz, “Genetic Discrimination and the Public Entities and Public Accommodations Titles of the Americans with Disabilities Act”, *American Journal of Human Genetics*, Vol. 53, 1993, 26.

²⁰ More: J.S. Alper, M.R. Natowicz, 26–32.

²¹ Having in mind that it is to do with conscious and intended action, the discriminator may not defend himself/herself by the argument that he/she did not intend to discriminate, and which is, by the way, used to justify discrimination. See Nevena Petrušić, “Teret dokazivanja”, *Sudska građanskopravna zaštita od diskriminacije* (ed. Nevena

of genetic discrimination is reflected in the fact that its victims are individuals, who, as already mentioned, do not have the genetic diseases symptoms or that it is not certain at all if they would be effected by such disease, so that they are not different at all from persons who might be used as comparators. For that reason, genetic discrimination is viewed within the context of genetic privacy,²² and the fight against genetic discrimination is based on the strict protection of individuals from unauthorized obtaining and using of genetic data.²³

Genetic discrimination may be one of the elements of, so called, multiple discrimination, when genetic characteristics of individuals incur as one of bases for their unequal treatment. Namely, the identity of a person make various personal characteristics, such as race, nationality, sex, genetic and other characteristics, so an individual may, at the same time, be discriminated on multiple grounds, which causes synergic harmful effect.²⁴

Genetic discrimination covers a wide spectrum of discriminating activities in interpersonal relations, both in the private and public spheres of life. Like all other forms of discrimination, genetic discrimination may also be made in the way to deny some right to a person, which is available to other persons, or some right is limited to him/her, while it is fully recognized to others, or a person is placed in a worse position by giving priority, i.e., a privilege to some other persons.²⁵

3. NORMATIVE FRAMEWORK OF PROTECTION AGAINST GENETIC DISCRIMINATION IN SERBIAN LEGAL SYSTEM

The normative framework of protection against genetic discrimination in domestic legal system comprises general antidiscrimination regu-

Petrušić), Poverenik za zaštitu od diskriminacije, Pravosudna akademija, Belgrade 2012, 273).

²² About the genetic privacy, in detail: Zorica Kandić-Popović, *Legal protection of basic human values in Central and East Europe and modern biotechnology: towards European harmonization*, Open Society Institute, Praga 1999, 73–77.

²³ See: Aart Hendriks, *Protection against genetic discrimination and the Biomedicine convention*, 216. <https://openaccess.leidenuniv.nl/bitstream/handle/1887/13932/Protection+against+genetic+discrimination+and+the+biomedicine+convention.pdf?sequence=2. asp>, 15.6.2015.

²⁴ See: Snježana Vasiljević, “Multiple discrimination”, *Žene i pravo: feminističke pravne teorije* (ur. Radačić, Ivana), Zagreb, Centar za ženske studije, 2009, 361–378.

²⁵ Thus, for example, an Employer may refuse to employ a person for whom, due to the family history, such employer presumes genetic predisposition for the disease, although the genetic profile, itself, is not relevant for the working capacity of an individual. Having in mind the consequences it have caused, it may be qualified as a breach of the principle of equal rights and liabilities, disturbing, humiliating treatment, hate speech, etc.

lations, contained in the Constitution of the Republic of Serbia and the Antidiscrimination Law, as well as some special regulations, directly or indirectly concerned with prevention and protection against genetic discrimination.

3.1. General Antidiscrimination Regulations

The principle of equality and antidiscrimination is proclaimed by the *Constitution of the Republic of Serbia*,²⁶ prescribing that “According to the Constitution and law, everybody is equal”, that “everybody is entitled to equal legal protection, without the discrimination, as well as that “any kind of discrimination is banned, direct or indirect, on any ground, and particularly on the grounds of race, sex, nationality, ethnicity, social origin, birth, religion, political and other opinion, financial standing, culture, language, age and psychical of physical disability”.²⁷

The general regime of discrimination ban is regulated by the *Anti-discrimination Law (ADL)*,²⁸ by means of the basic and general antidiscrimination laws. It regulates the general ban of discrimination, the form and discrimination cases, as well as the procedures for protection against discrimination. The ADL bans discrimination on the grounds of any personal features, and in the list of 20 named and exemplary stated personal features there are also the genetic characteristics. The ADL does not define the notion “personal feature”, or the notion “genetic characteristic”. In the theory and practice, there is a generally accepted attitude that “the personal feature” is a personal character of one person determining his/her physical, psychological, spiritual, economic or social identity, but the notion “genetic characteristic” has not been the subject of more specific elaboration of experts, nor has anything on its contents been commented by the legal practice.

The analysis of antidiscrimination rules contained in the Constitution and ADL indicates that the discrimination is universally banned in Serbia: discrimination ban is obligatory for anyone, the ban covers all segments of social relations, both in public and private spheres, and the ground for discrimination may be any personal feature, actual or presumed, including genetic characteristics, as well.

3.2. Regulations on the Rights of Patients / Subjects

For the suppression of genetic discrimination, the regulations on genetic testing agreement, regulation of confidentiality of genetic data, as well as the regulations on genetic discrimination ban are very important.

²⁶ *Official Gazette of RS*, No. 98/2006.

²⁷ Art. 21. paras 1 and 2 of the Constitution.

²⁸ Antidiscrimination Law (hereinafter ADL), *Official Gazette of RS*, No. 22/09.

These regulations are contained in laws, regulating the rights of patients and subjects included in biomedical researches.

The Law on the Rights of Patients as of 2013²⁹ in accordance with the principle of autonomy (self-determination),³⁰ expressly prescribes that without the approval of a patient no medical measures may be undertaken over him/her, except in some extreme cases, established by the law and which are in accordance with the physicians ethics.³¹ Having in mind the legal definition of a medical measure, which represents “any medical service provided for preventive, diagnostic, therapeutic and rehabilitation purposes”,³² this ban undoubtedly refers to genetic testing, as well, to which an individual may be subjected only if he /she agrees about that. The ban is also applicable in terms of genetic testing within the medical researches which may be conducted only with the agreement of the patient, given in a writing, which is expressly regulated by Law.³³

For genetic discrimination prevention, the regulations on medical data confidentiality are of the key significance, including data on genetic characteristics, considered as particularly sensitive data about the patients personality.³⁴ The obligation to keep the data confidentiality applies to all the employees in health institutions dealing with health business, all the employees working in organizations of mandatory health insurance, as well as the employees in organizations dealing with voluntary health insurance, which is strictly prescribed by the law.³⁵ From these provisions, it comes that genetic data may be available to private insurers, as well, which presents a problem, not only from the aspect of genetic privacy protection, but also from the aspect of discrimination prevention.

For genetic discrimination prevention, in Serbia, one of the most important laws is the mentioned *Law on Prevention and Diagnostics of Genetic Diseases, Genetically Conditioned Anomalies and Rare Diseases (LGDPD)*, of 2015. As already said, the purpose of this law is to improve the protection of genetic health and to regulate the reasons for, and condi-

²⁹ *Official Gazette of RS*, No. 45/13. (hereinafter LRP).

³⁰ More: Jakov Radišić, Hajrija Mujović Zornić, “Pomoć pacijentima u ostvarivanju njihovih prava: Zapadna Evropa kao uzor Srbiji”, *Jugoslovensko udruženje za medicinsko pravo*, Belgrade 2004, 11; Ivana Simonović, “Pravo na samoodređenje, autonomija volje i pravo pacijenta na informisani pristanak”, *Zaštita ljudskih i manjinskih prava u evropskom pravnom prostoru*– Colletion of papers), Volume one, School of Law in Niš, Niš 2011, 455–472.

³¹ Art. 15. LRP

³² Art. 2 para. 1, 2 LRP

³³ Art. 25 LRP

³⁴ Art. 21 LRP

³⁵ Art. 2 para. 2 LRP

tions of genetic testing.³⁶ Therefore, this law is important for effective prevention of genetic discrimination, and in that, the regulations on genetic privacy protection and genetic discrimination ban are particularly significant.

When it is to do with protection of genetic privacy, it might be said that the ZGBARB has mainly been harmonized with International standards in this field, but there are also some individual rules which have not been harmonized. According to ZGBARB, a patient is entitled to data confidentiality, which results from genetic testing, considered to be the data about the personality, particularly those, relating to health condition of a person. Besides, there is also prescribed the obligation to keep biological samples, used for analyses, under conditions which guarantee their safety and confidentiality,³⁷ in that, the violation of this obligation has not been misdemeanor sanctioned. The protection of genetic privacy is also ensured by regulations about the way of keeping the results of genetic testing. ZGBARB indicates that they are kept in accordance with the regulations on medical documentation and records, in the field of health and it expressly prescribes the duty of removing the results of a genetic test when requested by patient, that is, his/her legal representative.³⁸

To the end of privacy protection, there are also regulations about the usage of genetic samples. They may be used only for intended purposes they have been taken for, after which they are destroyed, but there have been regulated two exceptions. Namely, the samples may be used 1) for other medical and scientific purposes “in the measure where such usage is allowed by the law, or some other legal provisions”, or 2) if a patient, having been fully informed about the other intended purpose of his sample usage, gave his approval in writing.³⁹ Breaching of these regulations has been sanctioned by a fine.⁴⁰ It stems from the rules stated that a genetic sample given voluntarily by an individual person for an exactly specified purpose, may be used for some other medical and scientific purposes, without his/her being informed or giving approval regarding that. It is contrary to the self-determination right, top-ranked in the scale of human values, due to which it has been protected by all International le-

³⁶ LGDPD prescribed that genetic analyses may be performed only in tertiary health institutions, which caused turbulent reactions of biologists and molecular biologists. The Serbian Genetics Society – Medical Genetics Section requested for urgent change of the law in that part, in order to prevent closing of genetic laboratories. (Politika, 14.08.2015).

³⁷ Art. 8. LGDPD.

³⁸ Art. 23. LGDPD.

³⁹ Art. 22. LGDPD.

⁴⁰ Art. 36. para.1.4. An institution may pay a fine ranging from RSD 300.000 to 1.000.000, an entrepreneur, from RSD 300.000 to 500.000, and a responsible person in a legal entity and a medical worker may pay the fine, ranging from RSD 40.000 to 50.000.

gal documents and ethic codes in the field of biomedicine. On the other hand, these rules open the space for invasion of genetic privacy, thus creating an appropriate ground for genetic discrimination. For that reason, the rules of ZGBARB, in the part related to conditions of genetic samples usage, should be urgently changed and harmonized with contemporary bioethical standards.

For protection against genetic discrimination, the ZGBARB provision, expressly banning genetic discrimination is of immediate relevance. In the Art. 9 of ZGBARB, in the rubrum “Discrimination Ban in the Process of Genetic Testing”, it is prescribed that “*no one must be discriminated or brought into an unfavourable position due to his/her genetic characteristics, genetic features of his/her genetically related person, or due to the very taking or not taking genetic tests*”.

Such formulated antidiscrimination clause, due to its lack of precision and incorrect terminology, opens a series of disputable questions.

In the first place, objective and subjective ranges of this ban are not clear. Judging from the rubrum, it may be concluded that the discrimination ban, as of the Art. 9. of ZGBARB refers just to the genetic testing procedure, therefore, to the treatment (acting and not acting) of authorized persons when conducting genetic testing and genetic screening. However, the contents of the very provision do not specify in any way to what field the ban refers to, so it may be concluded that it refers to all fields,⁴¹ therefore, it is obligatory for everyone.

On the other hand, the legislator prescribes that “no one must be discriminated, or brought into an unfavourable position”. This provision may cause confusion because it could be concluded wrongly that “bringing somebody into an unfavourable position” is not discrimination, at all, but completely different treatment, banned by the legislator, as well. The general legal notion of discrimination, defined in the Art. 2 of ADL, however, cover acting which places in less favourable position an individual, that is, a group, due to some personal feature; then, it is to do with indirect discrimination, as one of legal forms of discrimination. It seems that the intention of the legislator was to ban both direct and indirect genetic discrimination by ZGBARB and that the errors in terminology, which incurred in formulation of antidiscrimination clause, were caused by wrong translation of foreign legal-technical terms: the term “discrimina-

⁴¹ It is interesting that the ZGBARB wording miss the provision contained in the Art. 9, para. 2 of the Law, anticipating that “any discrimination ban or the request for equal treatment”, provided by other laws and regulations in relation to para.1 of this Article, remain unchanged, and especially when these regulations are adopted to protect a specific group of persons”. Although this provision is quite unclear due to bad editorial, its sense may be hinted: that a special regulation ZGBARB about the ban of genetic discrimination does not exclude, or change the regulations on the ban of genetic discrimination contained in other laws.

tion”, was used in the meaning “disparate treatment”, and the term “unfavourable treatment”, in the meaning “disparate impact”. However, due to such terminology confusion, it may be disputable in practice whether only the direct genetic discrimination has been banned or the ban also applies to the indirect discrimination. On the other hand, in the context of discrimination it may not be spoken about placing a person in “more unfavorable position”, but in the “worse” position having in mind that indirect discrimination implies the comparison of the outcome of treatment, and the outcome is just the worse position of a discriminated person, compared to some other in an analogue situation. It is obvious that the law editors were not familiar with the general antidiscrimination notions.

Dilemmas challenge the rules of ZGBARB related to the basics of genetic discrimination. In the International Comparative Law the customary approach in regulating the genetic discrimination ban implies that discrimination is banned on the basis of actual or presumed genetic characteristics. ZGBARB, however, does not prescribe expressly that genetic discrimination may be made on the basis of presumed genetic characteristics. From the statement of the discrimination basis, it may be hinted that the legislator had the intention to do so, because, the discrimination of an individual is banned not only on the grounds of his/her genetic characteristics, but also on the basis of “*genetic characteristics of his/her genetically related person*”. However, due to non-existence of an express rule on genetic discrimination ban, based on presumed genetic characteristics and nomotechnically incorrect wording of the provision, discriminators have been given an opportunity to successfully defend themselves by proving that they were not familiar with genetic characteristics of a discriminated person, or genetic characteristics of persons he/she is related to, in genetic terms. The additional confusion may be caused by expressions, such as “*genetic characteristics*” and “*genetic features*” because they are not defined by ZGBARB, and in some legal provisions they have been used as synonyms.

Besides, when formulating the antidiscrimination clause, the legislator neglected the fact that the complex rules of human genetics were not known to everybody, and even to potential discriminators. Namely, the linguistic interpretation of the provision, as of the Art.9, suggests that genetic discrimination may be made if based on “genetic features” of a person with whom the discriminated person has been genetically related. In this way, the ranges of the genetic discrimination ban have been narrowed. Genetic discrimination may be made even when a discriminator presumes that a discriminated person has got certain genetic characteristics, basing his/her presumption on the fact that some family member of his/her family is affected by a genetic disease, with whom the discriminated person has not been genetically related at all.

It comes out from the ZGBARB provisions that only an individual for whom the discriminator knows or presumes to have certain genetic characteristics, may be exposed to genetic discrimination. His/her family members, however, may also be exposed to genetic discrimination, even though they are not genetically related to him/her, as well as persons close to him/her, that, based on the fact that they have been related to him/her. Thus, for example, the victim of genetic discrimination may be a spouse of a person, whom the discriminator knows about or presumes that he/she has got certain genetic characteristics. This possibility stems from the general definition of discrimination, contained in the Article 2 of ADL.

According to ZGBARB, the discrimination which occurs due to the very “*taking or not taking*” the genetic testing⁴² has also got the character of genetic discrimination. A circumstance that a person has undertaken genetic testing may be the basis for making a presumption about genetic characteristics, so that here, it is to do with discrimination on the basis of presumed genetic characteristics. However, extending the genetic discrimination to cases, refusing to participate in genetic testing, is primarily in the function of protection of the self-determination right in the field of genetic testing.

Finally, it is necessary to point out to the fact that ZGBARB takes into consideration the genetic discrimination of a person only, although there is a possibility to have a group of persons discriminated on this ground, both directly and indirectly. So, for example, an Insurance company may deny the life insurance right to all persons who have the Huntington disease gene identified. Having in mind the effects caused, genetic discrimination of a group of persons is more dangerous than genetic discrimination of an individual, and it is more difficult to discover and prove it than it is the case with genetic discrimination of a person.

The analysis of the antidiscrimination clause, as of the Art. 9 ZGBARB showed that the Legislator had not managed to regulate adequately the discrimination ban based on genetic characteristics – personal feature, encroaching the identity of an individual most profoundly. Although the purpose and the sense of incorporating the antidiscrimination clause in ZGBARB is reflected in the way that, starting from general legal definitions of certain forms of discrimination, it is to concretize typical conducts and situations in which the genetic discrimination is manifested in order to recognize this form of discrimination in practice more easily, the Legislator has just introduced confusion, and, essentially, narrowed the range of protection against genetic discrimination established by general antidiscrimination regulations.

ZGBARB does not prescribe special criteria for conducting the discrimination test, which is a key instrument for establishing discrimina-

⁴² Art. 9 ZGBARB (*in fine*).

tion. In the absence of special rules, there are applied the general rules contained in ADL. ZGBARB does not contain special rules on mechanisms of legal protection against genetic discrimination, so that they do not differ from mechanisms intended for protection against any other form and case of discrimination. It is important, however, that the Legislator, in regulating the misdemeanor legal protection, correctly considered the social danger of genetic discrimination, that being indicated by strict sanctions.⁴³

4. CONCLUDING REMARKS

Genetic discrimination is a complex phenomenon, causing a series of harmful effects both on the individual and social plan, respectively. In spite of the increased interest of scientists, genetic discrimination, its forms and manifestations, problems related to genetic discrimination discovering and proving, have not been fully and scientifically elaborated yet. Although there are not exact data on the spread of genetic discrimination in Serbia, it may be concluded, having in mind the experience of other countries, that it is not a far future in Serbia, but that it has already occurred and that it would be increasing in parallel with the increase of the number of people, included in genetic researches. In order it would not burst, it is necessary to take comprehensive and coordinated measures to prevent its manifestation.

The basic precondition for effective prevention and protection against genetic discrimination is the existence of a comprehensive and coherent normative framework. In the legal system of Serbia the framework of genetic discrimination protection comprises general antidiscrimination regulations, contained in the Constitution of Serbia and the Anti-discrimination Law, as well as the special regulations, related to genetic discrimination: regulations on the consent to genetic testing, regulations on genetic data confidentiality, as well as a regulation about the genetic discrimination ban.

The analyses of relevant regulations, contained in ZOPP and ZGBARB have shown that some legal solutions about the genetic privacy

⁴³ For violation of genetic discrimination ban an institution may pay a fine ranging from RSD 300.000 to 1.000.000, an entrepreneur, from RSD 300.000 to 500.000, and a responsible person in a legal entity and a medical worker may pay the fine, ranging from RSD 40.000 to 50.000 (Art. 36. para.1, 2 and 3. ZGBARB). Just for comparison, for discrimination in providing medical services, based on the health condition, the ADL prescribes fines, ranging from RSD 10.000 to 100.000, for legal persons and entrepreneurs and from RSD 5.000 to 50.000 for a responsible person and medical worker. Fines are much lower when it is to do with other forms and cases of discrimination. See: Nevena Petrušić, Mirjana Tugar, Branko Nikolić, *Priručnik za primenu prekršajnog antidiskriminacionog prava*, Poverenik za zaštitu ravnopravnosti, NCSC, Beograd 2015, 46.

protection are not in accordance with general antidiscrimination and bioethical standards. Although the work on ZGBARB (by which there has been regulated conducting of genetic testing for the first time in Serbia) offered an opportunity of making the genetic discrimination ban more concrete, and was worked out in detail, this opportunity has not been used properly. The rules on the use of genetic samples and availability of genetic testing results, of key importance for genetic discrimination prevention, have not been harmonized with modern ethical and legal standards. On the other hand, antidiscrimination clause, contained in the Art.9 of ZGBARB reduces the range of protection against genetic discrimination compared to the protection offered by the general Antidiscrimination Law. The Clause is not comprehensive, clear and precise, therefore it causes a lot of doubts, which can make the application of genetic discrimination ban regulations more difficult. Having in mind the harmful effects caused by genetic discrimination, there is a need to eliminate the observed normative failures in due time, and enable people enjoy the benefits provided by genetic testing without the fear of discrimination.

In order to prevent genetic discrimination, it is necessary to work on informing and raising awareness of the public about the genetic privacy and the problem of genetic discrimination, but also on the social justice promotion and developing sensibility for bioethical challenges brought about by the new age.