

## **Preserving the integrity of genetic heritage in the face of new therapeutic options: bio-legal considerations on genetic editing**

*A preservação da integridade do patrimônio genético diante de novas opções terapêuticas: considerações biojurídicas sobre a edição genética*

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**Summary:** 1. Introduction. 2. From curative medicine to predictive medicine: advances, ethical challenges, and new perspectives. 3. Gene editing practice and ecosophy. 4. The necessary preservation of human and environmental genetic heritage. 5. Conclusion. References.

**Abstract:** Article aimed at analyzing the biojuridical limits appropriate to the use of gene editing as a therapeutic protocol, without this practice violating the necessary preservation of the integrity of the human and environmental genetic heritage. From this perspective, we sought to assess the challenges in guaranteeing genetic integrity and diversity. The methodological path followed was the analytic-discursive,

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identifying fundamental connections related to the problem and interpreting the bioethical and biojuridical concepts in favor of the conclusion regarding the proposed problem. This is a bibliographic review, based on books, chapters in collective works and articles published in leading journals in the area. The use of new therapeutic options such as gene editing emerges in the current scenario as a tool of unknown proportions. Its means must always be used with clear ethical and legal limits to avoid the degradation of the genetic heritage. Add reflections about the new biotechnological paradigms in the era of the new genetics and the necessary legislative update so that there is a better protective standard.

**Keywords:** Genetic Editing; Diversity; Environment; Integrity; Genetic Heritage.

**Resumo:** Artigo destinado a analisar os limites biojurídicos adequados à utilização da edição genética como protocolo terapêutico, sem que esta prática viole a necessária preservação da integridade do patrimônio genético humano e ambiental. Nessa perspectiva, buscou-se avaliar os desafios na garantia da integridade e diversidade genética. O caminho metodológico percorrido foi o analítico-discursivo, identificando conexões fundamentais relacionadas à problemática e interpretando os conceitos bioéticos e biojurídicos em prol da conclusão quanto ao problema proposto. Trata-se de revisão bibliográfica, pautada em livros, capítulos em obras coletivas e artigos publicados em periódicos de referência na área. O emprego de novas opções terapêuticas como a edição genética desponta no cenário atual como uma ferramenta de proporções ainda desconhecidas. Os seus meios devem ser utilizados sempre com limites éticos e jurídicos claros para evitar a degradação do patrimônio genético. Agregar reflexões acerca dos novos paradigmas biotecnológicos na era da nova genética e a necessária atualização legislativa para que haja um melhor standard protetivo.

**Palavras-chave:** Edição Genética; Diversidade; Meio Ambiente; Integridade; Patrimônio Genético.

## 1. Introduction

The history of civilizations shows that technological advances bring about important changes in several scenarios, such as the social, legal, and economic ones. The expression of contemporary biotechnology has been generating a true landmark after large-scale advances, which reverberate impacts on human life, as well as on social relations. From the effervescence of the bioethical and legal aspects arising from genetics and, consequently, the development of new therapeutic and diagnostic methods in the health sciences, the influence of technologies and the growth of their use in medical relations became easy to perceive.

From this perspective, it is observed that genetic editing has been providing new contours in these relations, applying the use of systems by virtue of the provision of a specialized service. This technique has made possible new maneuvers in the design of therapeutic procedures, which has been changing the current scenario and leading to a new delineation in the models of modern medicine.

The destination of the therapeutic process and its objectives have gained a new form over the decades, no longer aimed only at curing the disease presented by the patient, but also to receive a new understanding about the concept of health. In this sense, medical assistance has shifted in search of ensuring the provision of an increasingly individualized care, considering the history, environment and particularities of each subject, with the aim of preventing future genetic diseases through predictive information.

In this sense, the present work seeks to analyze the appropriate legal limits for the use of genetic editing as a therapeutic protocol, without violating the necessary preservation of the integrity of genetic heritage. In this vein, the impacts of the practice of genetic editing as a therapeutic protocol in balance with the

environment were pondered, going through the main advances in the approach to this technique, from curative medicine to the use of new prediction techniques.

The research has a bibliographic and qualitative nature, having in view to seek, from specialized theoretical reference, the answer to the proposed problem, having as methodological path the deductive approach.

## **2. From curative medicine to predictive medicine: advances, ethical challenges, and new perspectives**

The process of evolution of medical practice shows new contours as to the destination and application of the approaches up to the contemporary models. Primarily, curative medicine, also known as assistance medicine, started the promotion of medical interventions aiming at the recovery of the patient's health. Thus, curative medicine was built based on health care from the onset of a pathological condition, with the aim of fully restoring health or, if not possible, to achieve an improvement that would allow greater comfort, aiming for the best possible result<sup>5</sup>.

In a broad way, the essence of the medical activity is linked until today to the ideal of curative medicine, because, since the beginning, the physician performs the treatment of diseases already installed in their organisms, reason why the doctrine and the dominant jurisprudence understand that the contractual obligation of the physician, in these cases, configures an obligation of means, and not of result<sup>6</sup>.

The preventive bias of medicine seeks the creation of conditions that maximize the quality of health of individuals and is translated through the understanding of three systematized strands for the control of determining factors: education, prevention and protection<sup>7</sup>. This tripod is based on the use of appropriate communication so that the health measures adopted protect collective health.

Thus, both approaches, when considered as alternatives for treatment, are seen as opposing poles, imposing health efforts to find the most appropriate option. The two forms of treatment are complementary, since both approaches, the curative and the preventive, are vital to the adequate conformation of the human being's health. For example, the treatment of diseases such as hypertension involves curative medicine, but, due to the need for health management, because it is a risk factor for other diseases, such as cerebral vascular disease or even hypercholesterolemia, it is necessary to act preventively, through therapeutic planning<sup>8</sup>.

Today, concepts such as precision medicine, individualized medicine or personalized medicine are relevant to medicine, and it is important to highlight

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<sup>5</sup> SEPÚLVEDA, DP. "La responsabilidad civil del médico en la medicina curativa". 2014. Tese (Doutorado em Direito) Departamento de Derecho Privado, Universidade Carlos III de Madrid - Getafe. Orientadora: María José Santos Morón. Disponível em: [https://e-archivo.uc3m.es/bitstream/handle/10016/19232/dario\\_parra\\_tesis.pdf](https://e-archivo.uc3m.es/bitstream/handle/10016/19232/dario_parra_tesis.pdf) Acesso em: 12 abr. 2021, p. 71-72.

<sup>6</sup> SEPÚLVEDA, DP. "La responsabilidad civil del médico en la medicina curativa". 2014. Tese (Doutorado em Direito) Departamento de Derecho Privado, Universidade Carlos III de Madrid - Getafe. Orientadora: María José Santos Morón. Disponível em: [https://e-archivo.uc3m.es/bitstream/handle/10016/19232/dario\\_parra\\_tesis.pdf](https://e-archivo.uc3m.es/bitstream/handle/10016/19232/dario_parra_tesis.pdf) Acesso em: 12 abr. 2021, p. 71-72.

<sup>7</sup> HESPANHOL, AP; COUTO, L; MARTINS, C. "A medicina preventiva". *Revista Portuguesa de Medicina Geral e Familiar*, v. 24, n. 1, p. 49-64, jan. 2008. Disponível em: <https://www.rpmgf.pt/ojs/index.php/rpmgf/article/view/10462/10198>. Acesso em: 29 abr. 2021, p. 50.

<sup>8</sup> LIFSHITZ, A. "La medicina curativa y la medicina preventiva: alcances y limitaciones". *Medicina Interna de México*, vol. 30, nº1, jan/fev, 2014. Disponível em: <https://www.medigraphic.com/cgi-bin/new/resumen.cgi?IDARTICULO=48339> Acesso em: 12 abr. 2021, p. 64.

them<sup>9</sup>. Based on the use of biomarkers, this approach enables the identification of particular genetic aspects, thus indicating the presence of oncological, genetic or even infectious diseases. The use of these biomarkers has been used to indicate therapeutic procedures, as well as the appropriate follow-up for each pathology. Faced with the three terminologies presented, the terminology "precision medicine" is the most used nowadays, because it takes into consideration other spheres, such as the environment to which the subject is inserted and their respective lifestyle<sup>10</sup>.

The use of individual information about the patient, such as comorbidities, habits, lifestyle and family history, was already a reality in medical practice. Added to the concept of precision medicine was the knowledge of Genetics, which allows the correlation between the patient's genetic information, the possibility of disease onset and the best alternatives for their treatment<sup>11</sup>.

The core of precision medicine lies in the search for the improvement of diagnosis and respective medical treatment. For the purpose of this approach, we seek the use of clinical data and scientific information to build strategies that enable an individualized and more assertive therapeutic process. In this perspective, specific tools are used in the integration and analysis of large amounts of clinical data for diagnosis, care and management<sup>12</sup>.

Oncology was the area in which precision medicine has shown the greatest development to date, consolidating the use of genetic tests as markers to identify therapeutic agents in cases of neoplasia in different tissues. The milestone in the use of these markers was the detection of HER-2 through the use of immunohistochemistry. Another advance in sequencing techniques came with the creation of next-generation genetic tests, making it possible to find more assertive drugs for neoplasms. João Pinho<sup>13</sup>, highlights that "new tests detect not only specific point mutations in different genes, such as large deletions and insertions, and even other more recently described types of mutations are being addressed - and are very important, especially for the immunotherapy of neoplasms."

It should be noted that the possibility of identifying and knowing "genetic alterations in hereditary conditions is associated with the development of personalized prophylactic and therapeutic alternatives, that is, aimed at the personal context of each patient, contributing to the prevention of cancer or the choice of a more precise and effective treatment"<sup>14</sup>. As examples of cancers arising from genetic predisposition known are "breast cancer, related to mutations in genes BRCA1 and BRCA2, and colon cancer, related to Lynch syndrome and familial adenomatous polyposis"<sup>15</sup>.

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<sup>9</sup> LIFSHITZ, A. "La medicina curativa y la medicina preventiva: alcances y limitaciones". *Medicina Interna de México*, vol. 30, nº1, jan/fev, 2014. Disponível em: <https://www.medigraphic.com/cgi-bin/new/resumen.cgi?IDARTICULO=48339> Acesso em: 12 abr. 2021, p. 64-65.

<sup>10</sup> PINHO, JRR. "Precision Medicine". *Einstein (São Paulo)*. 2017, v. 15, n. 1, p. 8-10. Disponível em: <https://doi.org/10.1590/S1679-45082017ED4016> Acesso em: 12 abr. 2021, p. 8-10.

<sup>11</sup> MEIRELLES, AT; GUINDALINI, R. "Oncogenética e dimensão preditiva do direito à saúde: A relevância da informação genética na prevenção e tratamento do câncer". In: MEIRELLES, Ana Thereza *et al* (Coords.). *Direito e Medicina: Interseções Científicas. Genética e Biotecnologia*. V.I. Belo Horizonte: Conhecimento, 2021, p. 157.

<sup>12</sup> HAENDEL, M; CHUTE, C; ROBINSON, P. "Classification, Ontology, and Precision Medicine". *The New England Journal of Medicine*, 2018, p. 1452-1462. Disponível em: <https://www.nejm.org/doi/full/10.1056/NEJMra1615014> Acesso em: 12 abr. 2021, p. 1453-1454.

<sup>13</sup> PINHO, JRR. "Precision Medicine". *Einstein (São Paulo)*. 2017, v. 15, n. 1, p. 8-10. Disponível em: <https://doi.org/10.1590/S1679-45082017ED4016> Acesso em: 12 abr. 2021, p. 8-10.

<sup>14</sup> MEIRELLES, AT; GUINDALINI, R. "Oncogenética e dimensão preditiva do direito à saúde: A relevância da informação genética na prevenção e tratamento do câncer". In: MEIRELLES, Ana Thereza *et al* (Coords.). *Direito e Medicina: Interseções Científicas. Genética e Biotecnologia*. V.I. Belo Horizonte: Conhecimento, 2021, p. 159.

<sup>15</sup> MEIRELLES, AT; GUINDALINI, R. "Oncogenética e dimensão preditiva do direito à saúde: A relevância da informação genética na prevenção e tratamento do câncer". In:

Thus, by evaluating each specific case, including genetic specificities, valuable information enables accurate decisions, valid only for the patient in question. Genomic medicine has contributed to the development of a predictive practice that promises to bear fruit. Based on the use of genetic tests, this branch allows the knowledge of genetic predispositions of the human being through high efficiency techniques. The result of these tests has generated a new horizon for medical practice that was not possible before: the construction of a medicine that unites the personalization of procedures with access to predictive information in a participatory manner<sup>16</sup>.

Unlike preventive medicine, where the development of healthy habits aims to reduce the possibility of the individual developing a disease, predictive medicine is intended to identify genetic predispositions of the patient and/or his family members to achieve an early diagnosis. This aspect has been gaining prominence from health technologies, of which artificial intelligence stands out. Therefore, the predictive approach has been presenting several benefits, which emerge interconnected to clinical and legal divergences.

Through genetic testing, predictive medicine indicates the predisposition of an individual or group of people to develop a certain disease. Therefore, its practice guarantees the patient an identification prior to the manifestation of the disease, enabling new forms of treatment, thus aiming at prevention and remedy. The effectiveness of this prognosis arising from testing at the phenotypic level depends on "the degree of interaction of the gene researched with the disease itself and the surrounding environment"<sup>17</sup>.

When there is a diagnosis of cancer at an earlier age than usual or there are several cases of the same neoplasm in close relatives, the hypothesis of predisposition to cancer can be raised, and people should be referred to genetic counseling and testing. If a germline mutation is identified, this person and his or her family will benefit significantly from personalized screening protocols and behaviors aimed at cancer prevention<sup>18</sup>.

Obtaining consent for testing is also a challenge in this relationship<sup>19</sup>. Nevertheless, patients point to fear of discrimination by insurers and employers when genetic information is accessed in health care planning. Marlene Braz<sup>20</sup> points out that informed consent gains even more importance in the perspective of predictive medicine, when considering the possible social risk, and it is up to the patient, in an autonomous condition, to weigh the pros and cons from the concrete case.

It is well known that the access to information of genetic nature unveils a series of ethical and legal issues related to the interpretation and use, within social relations in general, of this type of knowledge. One must take into account its purpose, which must be exclusively therapeutic, in favor of promoting the health of its holder and family. In this panorama, the sensitive data nature of the information and its consequent confidentiality must also be safeguarded, aiming at the

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MEIRELLES, Ana Thereza *et al* (Coords.). *Direito e Medicina: Interseções Científicas. Genética e Biotecnologia*. V.I. Belo Horizonte: Conhecimento, 2021, p. 159.

<sup>16</sup> PENA, SDJ. "Medicina genômica personalizada aqui e agora". *Revista Médica de Minas Gerais*, vol.20.3, 2010; p. 329-334. Disponível em: <http://rmmg.org/artigo/detalhes/365> Acesso em: 12 abr. 2021, p. 332-333.

<sup>17</sup> ASTONI JÚNIOR, I; IANOTTI, GC. "Ética e medicina preditiva". *Revista Brasileira de Saúde Materno Infantil*, 2010, v. 10, suppl 2, p. 377-382. Disponível em: <https://doi.org/10.1590/S1519-38292010000600016> Acesso em: 12 abr 2021, p. 378.

<sup>18</sup> DANCEY, J. E. *et al*. "The Genetic Basis for Cancer Treatment Decisions". *Cell*, 148, 2012, p. 409-420.

<sup>19</sup> EMALDI-CIRIÓ, A. "Biotecnologia e medicina individualizada: panorama ético-jurídico". In: CASABONA, CMR; DE SÁ, MFF (Orgs.). *Desafios jurídicos da biotecnologia*. Belo Horizonte, Editora Mandamentos, 2007, p. 200-201.

<sup>20</sup> BRAZ, M. "Conhecimento das informações genéticas: benefícios e riscos individuais". In: EMERICK, MC; MONTENEGRO, KBM; DEGRAVE, W. *Novas tecnologias na genética humana: avanços e impactos para a saúde*, 2007, p.185.

preservation of the fundamental right to privacy, here, related to the individualized dimension of genetics.

### 3. Gene editing practice and ecosophy

Genetic data is information related to an individual's genome. Through this type of knowledge, it becomes possible to identify predispositions for the development of genetic pathologies. The analysis of this information, in turn, exposes particularities about the genomic composition of the subject. Thus, the legal protection of genetic data must be in line with the rights of personality and with the effectiveness of the fundamental right to genetic intimacy.

The development of knowledge in Genetics affects several areas of people's lives. In this context, it is essential to bring Félix Guattari's thought about what he called "ecosophy". This is the articulation between the conceptions of natural, social and subjective environment, considered three ecologies that interact with each other with their knowledge of their ecological registers<sup>21</sup>.

The concept of ecosophy considers, precisely, the way individuals interact, among themselves, with society, and with the physical environment in which they are inserted. Although the idea of ecosophy is often associated with physical aspects of the ecosystems existing in the world<sup>22</sup>, one should pay attention to the fact that environmental issues can be broad, going beyond the fauna and flora bias and also reaching issues related to genetic manipulations.

Guattari's thought is developed from the consonance between environmental and social issues and subjectivation processes, applying this integration - the three ecologies - to the way human life is understood in a society marked by rapid technological changes<sup>23</sup>.

Access to the genetic heritage of living beings, an environmental issue that finds reflection in ecosophy, is an important and sensitive theme. The data from someone's genome is very personal and can bring risks to the freedom and identity of the individual. The delicacy intrinsic to the theme is glimpsed in its relationship with human dignity. Genetic data enable the elaboration of a very precise profile of the subject, adding physical characteristics, existing diseases and potential pathologies<sup>24</sup>.

With the success of the Human Genome Project, possibilities such as locating potentially disease-causing genes and sequencing fragments of DNA molecules of medical importance have been unveiled<sup>25</sup>. With this, searching for therapeutic alternatives for diseases, previously conceived as incurable, has become a possible reality. This identification occurs through genetic testing, bringing to the subject the opportunity to anticipate in up to decades the onset of a certain disease<sup>26</sup>.

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<sup>21</sup> GUATTARI, F. *As três ecologias*. Tradução Maria Cristina F. Bittencourt; Revisão da tradução Suely Rolnik. 21ª edição. Campinas, São Paulo: Papirus, 2012.

<sup>22</sup> RIVAROLI, APS; ALBERNAZ, RM. "O cuidado de si e as três ecologias: problematizando uma formação". *Revista Internacional de Formação de Professores*, v. 3, n. 4, p. 192-208, out/dez 2018. Disponível em: <https://periodicos.itp.ifsp.edu.br/index.php/RIFP/article/download/887/1027>. Acesso em 22 mar. 2022, p. 198-199.

<sup>23</sup> GUATTARI, F. *As três ecologias*. Tradução Maria Cristina F. Bittencourt; Revisão da tradução Suely Rolnik. 21ª edição. Campinas, São Paulo: Papirus, 2012.

<sup>24</sup> GALLARDO, MV. "Riesgo genético y discriminación". *Revista Derecho y Genoma Humano*, n. 33, p. 127-167, 2010. Disponível em: <https://dialnet.unirioja.es/servlet/articulo?codigo=3433175> Acesso em: 19 jan. 2021, p. 131-132.

<sup>25</sup> ROMEO CASABONA, CM. "Genética e Direito". In: ROMEO CASABONA, CM. *Biotecnologia, Direito e Bioética: perspectivas em Direito Comparado*. Belo Horizonte: Del Rey e Puc Minas, 2002, p. 25.

<sup>26</sup> MEIRELLES, AT. *Neoeugenia e reprodução humana artificial: limites éticos e jurídicos*. Salvador: Editora JusPODIVM, 2014, p. 100.

Access to genetic information, without any kind of intervention, has flagrant legal implications. However, with the possibility of using techniques such as genetic editing, the need to build an adequate protection of genetic heritage is enhanced.

Gene editing, especially after the advent of the CRISPR-Cas9 system, has made genomic modification much cheaper and more efficient<sup>27</sup>. For a long time, the available techniques demanded voluminous expenses and high labor time. However, with CRISPR-Cas9, the results have become more effective, being achieved with low investment and in just a few weeks<sup>28</sup>.

The emergence of new technologies implies the recognition of new rights. It is up to the Law, in its private and public perspectives, to regulate, establish limits of use and enable the application of modern technologies, dialoguing with other areas of knowledge in order to achieve adequate protection.

Genetic engineering practices, in which genetic editing is included, are proven forms of intervention in the environment. Such practices, identified in the light of anthropocentric environmental ethics, cause effects on the environment, since they culminate in the transformation of genetic heritage. For this reason, it is essential to think and establish legal limits for these interventions<sup>29</sup>.

Intervening in the genetic heritage of living beings requires compliance with human dignity. Even if the use of genetic editing has a therapeutic purpose, it is necessary to think about the quality of life and its substantial benefit. The effectiveness of the fundamental right, it is worth emphasizing, must occur in consonance with the ecological protection of the genetic heritage.

Thinking about genetic information refers to the composition of genetic identity. The genome of an individual manifests elements characterized by unrepeatability. Although the human species has a common genetic base, the genomic particularities of each individual make them unique<sup>30</sup>.

The individual genetic constitution is part of the formation of the identity of the person who, interacting in a society formed by similar members, but individualized in their genome, and therefore unique, holds the fundamental right to have their heritage and genetic identity protected<sup>31</sup>.

Accessing personal data implies visualizing subjective aspects of the individual. It identifies, from private information, consumption patterns, habits, aspirations<sup>32</sup>. Therefore, nowadays, holding information is a manifestation of power. Information has value.

Beyond the therapeutic bias, the practice of gene editing also reverberates in themes related to transgenesis. There is a tendency that biotechnology occupies more and more space in people's lives, comparing such impacts to the economic, social, and scientific effects generated by information technologies<sup>33</sup>.

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<sup>27</sup> MARFANY, G. "Interrogantes y retos actuales de la edición genética". *Revista de Bioética y Derecho*, n. 47, p. 17-31, nov. 2019. Disponível em <https://revistas.ub.edu/index.php/RBD/article/view/28551>. Acesso em 28 jul. 2022, p. 20-22.

<sup>28</sup> LACADENA, JR. "Edición genómica: ciencia y ética". *Revista Iberoamericana de Bioética*, n. 3, p. 1-16, 2017. Disponível em: <https://revistas.comillas.edu/index.php/bioetica-revista-iberoamericana/article/view/7665>. Acesso em 28 jul. 2022, p. 3.

<sup>29</sup> TRAJANO, T; VERDIVAL, R. "Engenharia genética como instrumento de intervenção humana no meio ambiente à luz do antropocentrismo". *Revista Jurídica Luso-Brasileira*, v. 7, n.5, p. 2225-2252, 2021. Disponível em: [https://www.cidp.pt/revistas/rjlb/2021/5/2021\\_05\\_2225\\_2252.pdf](https://www.cidp.pt/revistas/rjlb/2021/5/2021_05_2225_2252.pdf).

<sup>30</sup> BARACHO, JFA. "Identidade genética do ser humano: Bioconstituição: Bioética e Direito". In *Revista de Direito Constitucional e Internacional*. nº 32, 2000, p. 88-92.

<sup>31</sup> SPAREMBERGER, RF; THIESEN, AB. "O direito de saber a nossa história: identidade genética e dignidade humana na concepção da Bioconstituição". *Revista Direitos Fundamentais & Democracia*, v. 7, n. 7, p. 33-65, 2010.

<sup>32</sup> BIONI, BR. *Proteção de dados pessoais. A função e os limites do consentimento*. 2.ed. Rio de Janeiro: Forense, 2020.

<sup>33</sup> EPIFANIO, LES. "Segurança dos alimentos transgênicos e proteção constitucional dos direitos dos consumidores". In: CASABONA, CMR; SÁ, MFF (Orgs.). *Desafios Jurídicos da Biotecnologia*. Belo Horizonte: Mandamentos, 2007, p. 450.

Interventions in the genetic heritage of plant varieties, for example, harmonize financial and environmental savings. Some modifications aim to optimize or suppress the use of pest control chemicals, thus reducing environmental impacts. Genetic engineering techniques can contribute to making plants more tolerant to the effects of chemicals, while promoting crop resistance to pests themselves<sup>34</sup>.

When biotechnology is used in plants, animals, or microorganisms, genetically editing them, it is necessary to raise questions about the regulation pertaining to these genetically modified organisms. In this case, it is necessary to establish whether organisms considered to be transgenic should be under the same regulation as those understood as genetically modified<sup>35</sup>.

Returning to the human perspective, according to the doctrine of Ana Paula Myszczyk and Jussara Meirelles<sup>36</sup>, the genome is the greatest asset of the person and of humanity. With this, the individual becomes an autonomous source of biocapital, adding value and generating wealth.

The possibility of intervention in the genetic heritage, from laboratory procedures, highlights ethical and legal problems arising from the possibility of selective choices (therapeutic or not) interfering with the integrity of this genetic heritage, an objective of constitutional protection and fundamental legal good assigned, including, to future generations<sup>37</sup>.

In Brazil, there are researches aimed at the composition of databases fed with genetic information of the population, as is the case of the database created by researchers at the Center for Human Genome and Stem Cell Studies - CEGH-CEL - of the Institute of Biosciences at USP. The initiative gathered the DNA sequencing of 1,171 elderly people from the city of São Paulo, with an average age of 71 years old and unrelated. The survey identified more than 76 million genetic variations, 2 million of which were unpublished<sup>38</sup>.

Based on this type of collection, Ana Myszczyk and Jussara Meirelles question how surveys of this nature can contribute positively to improving the quality of life of the population without anyone appropriating the ownership of the human genome<sup>39</sup>.

One has, therefore, when thinking about the legal protection of genetic heritage, the recognition of this legal asset as a manifestation of fundamental rights, and its legal protection should occur from the effectiveness of fundamental rights in the light of ecosophy.

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<sup>34</sup> EPIFANIO, LES. "Avanços biotecnológicos e meio ambiente: implicações ética e jurídicas da Biossegurança". In: CASABONA, CMR; QUEIROZ, JF (Orgs.). *Biotecnologia e suas implicações ético-jurídicas*. Belo Horizonte: Del Rey, 2004, p. 382.

<sup>35</sup> MARFANY, G. "Interrogantes y retos actuales de la edición genética". *Revista de Bioética y Derecho*, n. 47, p. 17-31, nov. 2019. Disponível em <https://revistes.ub.edu/index.php/RBD/article/view/28551>. Acesso em 28 jul. 2022, p. 21.

<sup>36</sup> MYSZCZYK, AP. MEIRELLES, J. "Genoma humano, desenvolvimento científico e século XXI: construções de bases interpretativas biojurídicas iluminadas pela obra de Carlos María Romeo Casabona". *Revista da Faculdade Mineira de Direito*, v. 23, n. 46, 2020, p. 202-223. Disponível em: <http://periodicos.pucminas.br/index.php/Direito/article/view/24705/17464>. Acesso em 21 mar. 2022, p. 207.

<sup>37</sup> MEIRELLES, AT; TRAJANO, T. "A informação genética diagnóstica em procriação sob o argumento do direito à saúde e a preservação da naturalidade do patrimônio genético em face do pressuposto da alteridade". *Revista Jurídica Luso-Brasileira*, v. 4, n.4, p. 101-128, 2018. Disponível em: [https://www.cidp.pt/revistas/rjlb/2018/4/2018\\_04\\_0101\\_0128.pdf](https://www.cidp.pt/revistas/rjlb/2018/4/2018_04_0101_0128.pdf), p. 116.

<sup>38</sup> BEZERRA, M. "Pesquisa da USP cria maior banco de dados genéticos da população brasileira". *UOL*. Disponível em: <https://www.uol.com.br/tilt/noticias/redacao/2020/09/23/genoma-brasileiros-criam-maior-banco-de-dados-genericos-da-america-latina.htm>. Acesso em 17.abr.2021.

<sup>39</sup> MYSZCZYK, AP. MEIRELLES, J. "Biotecnologia, genoma humano e patrimônio comum da humanidade: um olhar a partir da proteção da biodiversidade brasileira". In: FREIRE DE SÁ, MFF; et. al (coord.). *Direito e Medicina: interseções científicas*. Genética e Biotecnologia. Volume I. Belo Horizonte: Conhecimento Editora, 2021, p. 361.



The incidence of the practice of therapeutic gene editing brings, beyond the medical aspect, issues that touch both the modification of the human genome and its social impacts, since the right to health is a social right.

Helen Nissenbaum<sup>40</sup>, a professor at Cornell Tech, Cornell University, argues that the greatest concern of people whose genetic data is processed is not simply the level of restriction on the use of this information, but the inappropriate use of this knowledge.

In order, then, to establish appropriate limits and guidelines for the practice of gene editing as a therapeutic protocol, making it compatible with the necessary guarantee of protection for genetic heritage, it is necessary to understand how practices intervening in the genome of living beings, including human beings, impact the environment, understood from its three registers that interact and influence each other.

#### **4. The necessary preservation of human and environmental genetic heritage**

Human genetic heritage is a legal good that has an intrinsic relationship with issues such as consent and intimacy, which differentiates it from other legal goods<sup>41</sup>. It is a fundamental right, simultaneously, in the dignity of the person and the ecologically balanced environment. For this reason, it is not sufficient that such right be conceived, merely, as a diffuse interest, but that it be, in truth, effected as an unfolding of a fundamental right<sup>42</sup>.

Genetic editing allows altering the DNA of a living being, inserting, removing, or modifying characteristics. With CRISPR-Cas9, the current editing technology, genomic interventions are more precise and cheaper, which allows thinking about a wider use in the coming years.

Since the 20th century, there have been increasing biotechnological and genomic advances, which may even affect future generations. In the face of the horizons that are opening up, a bioethical-legal debate arises about the limits of the use of genetic editing in relation to the integrity and preservation of genetic heritage. This is an issue directly related to the protection of human dignity<sup>43</sup>.

From the point of view of Bioethics, traditionally, one thinks of the two branches that emerged simultaneously between the 1960s and 1970s: Global Bioethics, by Potter<sup>44</sup>; and Medical Bioethics of the Georgetown model, forming conceptions grounded in issues of human health and environmental protection<sup>45</sup>. Environment and health are fundamental elements of the study of Genetics, which is

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<sup>40</sup> NISSENBAUM, H. *Privacy in Context. Technology, policy and the Integrity of Social Life*. Stanford University, 2010. Disponível em: [www.jstor.org](http://www.jstor.org). Acesso em: 09 abr. 2021, p. 2.

<sup>41</sup> NAVES, B; GOIATÁ, S. "Direitos Humanos, patrimônio genético e dados genéticos humanos: crítica à doutrina dos dados genéticos como interesse difuso". *Revista Bioética y Derecho*, n. 40, p. 63-81, 2017. Disponível em: <https://revistes.ub.edu/index.php/RBD/article/view/19163/21617>. Acesso em 25 jul. 2022, p. 70.

<sup>42</sup> NAVES, B; GOIATÁ, S. "Direitos Humanos, patrimônio genético e dados genéticos humanos: crítica à doutrina dos dados genéticos como interesse difuso". *Revista Bioética y Derecho*, n. 40, p. 63-81, 2017. Disponível em: <https://revistes.ub.edu/index.php/RBD/article/view/19163/21617>. Acesso em 25 jul. 2022, p. 79.

<sup>43</sup> NAVES, B; GOIATÁ, S. "Direitos Humanos, patrimônio genético e dados genéticos humanos: crítica à doutrina dos dados genéticos como interesse difuso". *Revista Bioética y Derecho*, n. 40, p. 63-81, 2017. Disponível em: <https://revistes.ub.edu/index.php/RBD/article/view/19163/21617>. Acesso em 25 jul. 2022, p. 69.

<sup>44</sup> POTTER, VR. *Bioética: ponte para o futuro*. São Paulo: Edições Loyola, 2016.

<sup>45</sup> FERRER, JJ; ÁLVAREZ, JC. *Para fundamentar a bioética. Teorias e paradigmas teóricos na bioética contemporânea*. Tradução de Orlando Soares Moreira. São Paulo: Edições Loyola, 2005, p. 63.

why it is necessary to conceive of the impacts of gene editing from both an environmental and health perspective.

The current state of gene editing is a considerable biomedical advance. However, because it is a cheaper and more accessible practice, its contours have raised questions about the protection of genetic heritage. This greater ease of access has made it possible for interested parties outside of laboratories to perform the protocol without any kind of supervision. Besides the fears arising from biohackers, some studies point to the possibility of permanent damage from unexpected results. Thus, it is essential to understand the importance of the concepts of integrity and vulnerability for the delineation of legal protection.

The reception of the concept of integrity, at the individual level, for microbioethics, touches on the concept of vulnerability. The meaning of the word evokes the idea of maintaining the state of completeness of the asset to be protected. Just like vulnerability, integrity appears in national and international texts in the quest to protect individuals against biotechnological advances. The Declaration of Helsinki raised the concept in question, from a biomedical perspective to the level of law<sup>46</sup>.

The Universal Declaration on Bioethics and Human Rights (UDHR), in its article 8, proclaims the need for protection of human vulnerabilities to the advancement of technologies applied to medical practices, and that individuals should have their individual integrity protected and respected<sup>47</sup>. In an evaluation based on macrobioethics, it is observed that this protection of integrity and diversity can not only be extended to the environment, as the Federal Constitution of 1988, originally brings this content in its art. 225.

It is worth mentioning that concepts such as Ecogenetics and Epigenetics show the influence that certain environments have on phenotypic manifestations. Studies show that genetic predispositions and mutations can be materialized when the subject meets specific environmental agents. The relationship between health and environment positions people as members of nature, rejecting anthropocentric optics by which the human species is seen as an external observer<sup>48</sup>.

As taught by Naves, Fernandes, and Nascimento, the term "ecogenetics" expresses the "influence of environmental factors on the triggering of diseases linked to specific gene alterations, affecting the health of individuals"<sup>49</sup>. In other words, it is the study of the multiple variables existing in the interaction between genotype and phenotype, seeking to understand how the environment influences genetic manifestations.

Considering that health and environment interact, setting limits to gene editing means finding balance. Recent studies point to the possibility of using the

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<sup>46</sup> DE MORAIS, TCA; MONTEIRO, PS. "Conceitos de vulnerabilidade humana e integridade individual para a bioética". *Revista Bioética*, vol. 25, n. 2, p. 311-319. 2017. Disponível em: <https://doi.org/10.1590/1983-80422017252191>. Acesso em: 20 jun. 2022.

<sup>47</sup> UNESCO. *Declaração Universal sobre Bioética e Direitos Humanos*. Trata das questões éticas relacionadas à medicina, às ciências da vida e às tecnologias associadas quando aplicadas aos seres humanos, levando em conta suas dimensões sociais, legais e ambientais. Cátedra UNESCO de Bioética da UnB. 2005. Disponível em: [http://bvsmms.saude.gov.br/bvs/publicacoes/declaracao\\_univ\\_bioetica\\_dir\\_hum.pdf](http://bvsmms.saude.gov.br/bvs/publicacoes/declaracao_univ_bioetica_dir_hum.pdf) Acesso em: 12 abr. 2022.

<sup>48</sup> REIS, E; NAVES, B. "Epigenetics and environmental bioethics". *Veredas do Direito*, v. 13, n. 26, p. 61-80, mai./ago. 2016. Disponível em: <http://revista.domhelder.edu.br/index.php/veredas/article/view/863>. Acesso em 25 jul. 2022, p. 66;

<sup>49</sup> NAVES, B; FERNANDES, F; NASCIMENTO, S. "Genética e meio ambiente: decorrências éticas e jurídicas da ecogenética". *Revista de Direito Sanitário*, v. 18, n. 1, p. 13-36, mar./jun. 2017. Disponível em: <https://www.revistas.usp.br/rdisan/article/view/135337>. Acesso em 25 jul. 2022, p. 16.

technique to treat serious diseases, such as AIDS<sup>50</sup> and leukemia<sup>51</sup>. On the other hand, many bioethicists point out that non-therapeutic applications may trigger neoeugenic practices<sup>52</sup>. The creation of legal control mechanisms depends on bioethical analyses about what is morally acceptable when thinking about interventions in the genetic heritage of humanity.

The ecological approach to genetics takes into account the different ways in which individuals respond to the influence of their environment. A person may have a gene that makes them more susceptible to developing a certain pathology, but this does not mean that the disease will manifest itself, because exposure to the environment can increase or decrease the chances of incidence. This makes the environment a decisive factor for the emergence of a disease<sup>53</sup>.

In the context of Ecogenetics, subjects can undergo genetic mutations when exposed to chemical agents, potent drugs, or radiation exposure. However, family and social environment, intrauterine environment, smoking, alcoholism and stress are also considered influencing factors. The effects, in turn, depend both on the genetic susceptibility of the individual, as well as variables such as time and intensity of exposure to the environmental element<sup>54</sup>.

A 2015 study identified signs of post-traumatic stress in children who were not exposed to the trauma situation as their parents. It was the first demonstration of epigenetic changes in both trauma-exposed parents and non-exposed children, drawing attention to intergenerational effects resulting from environmental influence<sup>55</sup>.

The mentioned research sheds light on the possibility of trauma in humans being transmitted to the next generation by epigenetic changes. According to Reis and Naves, this would corroborate the idea that the environment can affect the human genome in an intergenerational manner. The environment, although it does not transform DNA itself, can collaborate to the transmission of genetic markers responsible for the manifestation of gene characteristics<sup>56</sup>.

The possibility of interference of environmental conditions in the genome and human health makes the need for care with certain at-risk populations even more flagrant. This care, in turn, should be extended to future generations, in a sustainable development perspective that links environmental quality and health risk control<sup>57</sup> (NASCIMENTO, 2018).

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<sup>50</sup> URNOV, F *et al.* "Genome editing with engineered zinc finger nucleases". *Nature Reviews Genetics*, 11, p. 636-646, set. 2010. Disponível em: <https://doi.org/10.1038/nrg2842> Acesso em 28 jul. 2022.

<sup>51</sup> LI, H *et al.* "Applications of genome editing technology in the targeted therapy of human diseases: mechanisms, advances and prospects". *Signal Transduction and Targeted Therapy*, v. 5, n. 1, jan. 2020. Disponível em: <https://doi.org/10.1038/s41392-019-0089-y> Acesso em 28 jul. 2022.

<sup>52</sup> HABERMAS, J. *O futuro da natureza humana: a caminho de uma eugenia liberal?* São Paulo: Martins Fontes, 2004.

<sup>53</sup> RAMOS, AVGFF. *Vida humana: da manipulação genética à neoeugenia*. Rio de Janeiro: Lumen Juris, 2015, p. 42.

<sup>54</sup> OMENN, G; ARNO, M; SHARP, R. "Genetics and environment in human health". In: POST, Stepehn G. (Ed.). *Encyclopedia of Bioethics*. v. 2. 3ª ed. p. 966-970. New York: Mcmillan Reference USA, 2004.

<sup>55</sup> YEHUDA, R *et al.* "Holocaust exposure induced intergenerational effects on FKBP5 methylation". *Biological Psychiatry*, v. 80, p. 372-380, 2015. Disponível em: <https://doi.org/10.1016/j.biopsych.2015.08.005>. Acesso em 25 jul. 2022.

<sup>56</sup> REIS, E; NAVES, B. "Epigenetics and environmental bioethics". *Veredas do Direito*, v. 13, n. 26, p. 61-80, mai./ago. 2016. Disponível em: <http://revista.domhelder.edu.br/index.php/veredas/article/view/863>. Acesso em 25 jul. 2022, p. 78.

<sup>57</sup> NASCIMENTO, S. "Sustentabilidade e memória epigenética: o controle da qualidade ambiental para preservação das características genéticas das gerações futuras". In: CARMO, V; CHAVES, V; ROCHA, JC (org.). *Direito e Sustentabilidade I*. Florianópolis: CONPEDI, 2018. Disponível em:

It should be noted that the ecogenetic approach to health can assist the establishment of limits to gene editing. Genome and environment interact and influence the calculation of risks and probabilities of pathology manifestation. Thus, this form of knowledge contributes to thinking more effective ways of predictive diagnosis and genomic screening. Consequently, once these variables are identified, the therapeutic application of techniques such as CRISPR-Cas9 becomes more efficient.

At the current moment, the scientific community has been based on some bioethical criteria regarding the use of gene editing in human beings. One of them is the therapeutic purpose, especially when it comes to the treatment of serious diseases. As Lacadena highlights, this technique should be used to treat pathologies that do not have less dangerous therapeutic alternatives for the patient, in a beneficence analysis<sup>58</sup>.

In addition, the modification of the human genome should be restricted to somatic cells, that is, those in which the changes are not hereditarily transmitted to offspring. According to Josep Santaló, gene editing in somatic cells tends to be more ethically acceptable, because, it welcomes the autonomy of the individual, besides not being so different from other forms of experimental treatment<sup>59</sup>.

Applying tools such as CRISPR-Cas9, considering the influence of the environment on genomic manifestations, shows to be an appropriate conduct to harmonize ecogenetic knowledge. Environment and health are concepts that should be investigated and applied in consonance, to promote the guarantee of human dignity, the ecologically balanced environment and the protection of genetic heritage.

Since the environment influences the manifestation of genomic characteristics, legal protection must be on two fronts: to enable the development of therapeutic tools capable of treating serious diseases, and to guarantee environmental aspects that beneficially influence phenotypic manifestations, based on the idea of preservation of genetic heritage and ecological protection.

## 5. Conclusion

The clinical approach regarding therapeutic processes has gained new contours over the decades, migrating from a merely curative perspective to receive a new practice, more precise, individualized, and influenced by new technologies. The challenge is to harmonize the application of predictive medicine with the preservation of fundamental legal goods related to genetic data.

Thus, the use of genetic editing, in the practice of predictive medicine, generates a new paradigm for the areas of Health and Law, with the rise of implications regarding access to human DNA and transformations in nature. Perspectives connected to incurable diseases and therapeutic protocols, as well as the very relationship of the human being with fauna and flora gain repercussions under the veil of the technologies in question, thus requiring greater attention in the protection of fundamental rights, as well as attention in the conduct of the guidelines and recommendations that involve them.

These new interactions, between human beings, the environment, and their fellow creatures, consolidate a scenario in front of Ecosophy. The ecosophical line can generate benefits, as an instrument of reflection of these new paradigms, outlining a

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<http://site.conpedi.org.br/publicacoes/0ds65m46/38nlxj46/k777vM9314NX5825.pdf>. Acesso em 25 jul. 2022, p. 24.

<sup>58</sup> LACADENA, JR. "Edición genómica: ciencia y ética". *Revista Iberoamericana de Bioética*, n. 3, p. 1-16, 2017. Disponível em: <https://revistas.comillas.edu/index.php/bioetica-revista-iberoamericana/article/view/7665>. Acesso em 28 jul. 2022, p. 9.

<sup>59</sup> SANTALÓ, J. "La mejora genética humana en los tiempos del CRISPR/Cas9". *Revista de Bioética y Derecho*, n. 47, p. 33-41, nov. 2019. Disponível em: <https://doi.org/10.1344/rbd2019.0.28376> Acesso em 28 jul. 2022.

path so that biotechnological advances do not necessarily imply in the deterioration of the environment and of the human genetic patrimony itself.

It is thus up to Bioethics and Law to promote parallel monitoring of this new scenario, where a new relationship between the subject, the other, and the environment is established, contemplating normative updates, whether ordinary or deontological, capable of receiving the necessary changes to protect life and the environment.

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