

# Are Genetic Patents Morally Right?

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## I. Introduction

In the evolving landscape of medical science and biotechnology, the question of whether genetic patents are morally justified presents a complex ethical issue. The story of Henrietta Lacks and the use of her cells, known as HeLa cells, serves as a pivotal case study in understanding this issue. This article delves into various aspects of gene patenting, exploring its ethical implications from the perspectives of consent, scientific research, donor rights, and religious beliefs. By examining these factors, the article aims to provide a comprehensive overview of the moral dilemmas posed by genetic patents.

## II. Case Study

In 1951, the scientific community made a monumental breakthrough by cloning and cultivating the first human cells in a laboratory.<sup>1</sup> These were cervical cancer cells taken from Henrietta Lacks and were later known as “HeLa cells.”<sup>2</sup> Their significance lies in their unique “immortality.”<sup>3</sup> Unlike most cells that die after dividing a few times, HeLa cells continued to divide indefinitely.<sup>4</sup> This characteristic rendered them invaluable for scientific experiments, particularly in cancer biology and infectious disease research.<sup>5</sup> Following the discovery of their “immortality,” HeLa cells were commercialized and extensively distributed within the medical research community, leading to significant medical progress, generating billions of dollars for pharmaceutical and medical research industries.<sup>6</sup>

Yet, the narrative of HeLa cells also brought to light grave ethical issues, chiefly concerning consent. Henrietta Lacks, a poor African American woman, had her cells taken without her knowledge or consent during treatment at Johns Hopkins Hospital.<sup>7</sup> These cells, with their sensitive genetic data, were lucratively commercialized by multinational corporations.<sup>8</sup> Despite the profits, Henrietta Lacks' family received no financial benefits for decades.<sup>9</sup> This case highlights not only the ethical dilemmas around consent in medical research but also the racial and socioeconomic inequalities, particularly considering Henrietta Lacks' background.

The mid-20th century saw a void in clear legal and ethical guidelines regarding the use of human tissues in research.<sup>10</sup> This gap led to considerable ambiguities around the ownership and application of human biological materials. Henrietta Lacks' story was instrumental in transforming this scenario. In response, the United States has greatly enhanced its regulations

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<sup>1</sup> See *Informed Consent in Medicine: The Story of Henrietta Lacks Ethics Dilemma*, THE LAW OFFICES OF JAMES L. ARRASMITH (Aug. 12, 2023), <https://www.jlegal.org/blog/informed-consent-in-medicine-the-story-of-henrietta-lacks/>.

<sup>2</sup> *Id.*

<sup>3</sup> *Id.*

<sup>4</sup> See *id.*

<sup>5</sup> See *id.*

<sup>6</sup> See *id.*

<sup>7</sup> See *id.*

<sup>8</sup> See *id.*

<sup>9</sup> See *id.*

<sup>10</sup> See *id.*

and ethical standards in biomedical research.<sup>11</sup> These improvements, evolving since the mid-20th century, emphasize informed consent, ensuring protection for individuals' rights and aiming to avert similar exploitative practices in future research.

### III. Concerns

Despite clearer regulations and enhanced ethical standards in medical research, discoveries in the human genome and the expanding patent system have introduced new ethical dilemmas concerning the patenting of human genetic material.

#### *a. Owning the Human Body*

The human body should not be patentable. Doing so disturbs the sanctity and dignity of human life. The human genome is the creation of nature, thereby modifying (e.g., cloning) and patenting human genes threatens nature and the life of living beings.<sup>12</sup> Since the human body, cells, and genome are common to everyone, companies have no right to profit from something so common to all, like genetic structure or material.<sup>13</sup>

Moreover, the concept of bodily autonomy, a person's right to their genetic material, intersects with broader social issues, including feminism and abortion rights. This connection was notably highlighted in 1996 when women's rights leaders strongly opposed the patenting of genes linked to breast cancer.<sup>14</sup> They argued that such practices constituted an attack on women, stripping them of control over their genetic makeup.<sup>15</sup> This stance was supported by prominent figures in women's health organizations from sixty-nine countries, including Betty Friedan, Gloria Steinem, and Bella Abzug, a former member of Congress and breast cancer survivor.<sup>16</sup> Abzug firmly stated, "Human genes are not for sale or profit. Any attempt to patent human genetic materials by individuals, scientific corporations, or other entities is unacceptable."<sup>17</sup>

#### *b. Genetic Testing & Treatments*

Patenting genetic material can significantly restrict access to treatments and diagnostic testing by creating monopolies. For instance, when a gene linked to a specific disease is patented, the patent holder becomes the exclusive provider of diagnostic tests related to that gene.<sup>18</sup> This monopoly allows them to control the availability of testing services, potentially blocking other laboratories or companies from offering more affordable or innovative testing options.<sup>19</sup>

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<sup>11</sup> *See id.*

<sup>12</sup> *See Ethics and Laws of patenting Genes and Life Forms*, BREALANT (Jun. 27, 2023), <https://www.brealant.com/patenting-genes-and-life-forms-laws-and-ethical-issues/>.

<sup>13</sup> *See id.*

<sup>14</sup> *See* Daniel J. Kevles & Ari Berkowitz, *The Gene Patenting Controversy: A Convergence of Law, Economic Interests, and Ethics*, 67 *BROOK. L. REV.* 233, 242 (2001).

<sup>15</sup> *See id.*

<sup>16</sup> *See id.* at 243.

<sup>17</sup> *Id.*

<sup>18</sup> *See What are Gene Patents and are they Ethical?*, MINESOFT, <https://minesoft.com/what-are-gene-patents-and-are-they-ethical/>.

<sup>19</sup> *See id.*

Such monopolies inevitably lead to increased costs for treatment and testing.<sup>20</sup> Additionally, the patent owner may impose licensing requirements and fees on researchers who wish to study these genes.<sup>21</sup> This not only hinders scientific progress but also contributes to escalating costs for genetic tests and treatments.

As a consequence of the patent holder's ability to set high prices in the absence of competition, treatments and testing can become prohibitively expensive, especially for low-income individuals.<sup>22</sup> This creates a significant barrier to accessing essential healthcare services and advances, underscoring a critical ethical issue in the patenting of genetic material.

### *c. Scientific Research & Discovery*

Patents, particularly in the field of gene research and discovery, act as a barrier to competition and innovation. They restrict other companies from utilizing patented genes to develop alternative commercial products or solutions.<sup>23</sup> Moreover, patents can impede the progress of discovery and development in this field. They limit access to crucial genetic information and obstruct the free exchange of ideas and data, which is vital for scientific collaboration.<sup>24</sup> This limitation is especially detrimental to publicly funded or non-profit research institutions.<sup>25</sup> Consequently, the development of essential treatments, diagnostic tests, and other technologies can be significantly delayed or even remain undiscovered due to these constraints imposed by patents.

### *d. Donors*

Numerous issues arise regarding the use of donated genetic material in gene discovery and the subsequent patenting of these discoveries. A primary concern is compensation; donors often do not receive a share of the profits generated from their genetic contributions, even though these can lead to the development of lucrative medical treatments and products.<sup>26</sup>

Consent is another significant issue. Frequently, genetic material is obtained from donors without their full consent.<sup>27</sup> Many are not adequately informed that their genetic material could be used for commercial purposes or patented, leading to ethical concerns.<sup>28</sup>

Control over the use of donated genetic material is a further point of contention. Once patented, donors generally lose any say in how their genetic material is utilized.<sup>29</sup> They might be unaware of or disagree with the purposes for which it is used, yet they lack legal means to influence these decisions.<sup>30</sup>

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<sup>20</sup> *See id.*

<sup>21</sup> *See id.*

<sup>22</sup> *See id.*

<sup>23</sup> *See id.*

<sup>24</sup> *See id.*

<sup>25</sup> *See id.*

<sup>26</sup> *See Sirpa Sopini et al., Patenting and Licensing in Genetic Testing: Ethical, Legal and Social Issues*, 16 EUR. J. HUM. GENETICS 1, 26 (2008).

<sup>27</sup> *See id.* at 8.

<sup>28</sup> *See id.*

<sup>29</sup> *See id.* at 3.

<sup>30</sup> *See id.*

Lastly, privacy concerns are paramount. The use of genetic material for patenting raises serious questions about confidentiality, especially if the usage could potentially disclose sensitive information about the donor or their family.<sup>31</sup> Even small samples of genetic material can reveal extensive personal data, such as disease susceptibility, physical characteristics, and potentially behavioral traits.<sup>32</sup> Moreover, once patented, genetic material can be shared with or sold to third parties like pharmaceutical companies, extending its use beyond the donor's original intent and potentially exposing their genetic information more broadly than anticipated.<sup>33</sup>

#### *e. Religion*

Ethical concerns about gene patenting also emerge from religious perspectives. Many faiths view the ownership of human body parts as a violation of the natural order established by a higher power. This viewpoint was notably expressed in 1995, when 180 religious' leaders from eighty denominations united to oppose the patenting of human genes and genetically altered animals.<sup>34</sup> Richard Land, President of the Christian Life Commission of the Southern Baptist Convention, emphasized this concern, stating, "the patenting of human genetic material attempts to wrest ownership from God and commodifies human biological materials and, potentially, human beings themselves."<sup>35</sup>

Furthermore, various religions perceive gene manipulation and patenting as an overreach akin to "playing god", asserting undue ownership and control over life's fundamental elements.<sup>36</sup> They advocate for a reverence for the creation as it is, suggesting that the alteration and patenting of genetic material infringe upon the principles of respecting creation and the sanctity of life.<sup>37</sup> In this view, patenting genes, especially human genes, reduces life to a mere commercial entity, undermining its inherent value and dignity.

#### *f. Outlook*

The story of Henrietta Lacks has catalyzed significant changes in the realm of consent and the use of biospecimens in research. Today, the landscape is markedly different from the 1950s, with more stringent rules in place to protect individuals. It's crucial to recognize that Henrietta Lacks's case is exceptional; it's rare for biospecimens from a single individual to be as valuable as hers were.<sup>38</sup> Typically, scientific discovery relies on data from hundreds or even hundreds of thousands of people.<sup>39</sup> Identifying the source of a genetic sample, especially when identifiers are removed, usually requires deliberate effort, technical capability, and a specific motive to use this information.<sup>40</sup>

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<sup>31</sup> *See id.* at 8.

<sup>32</sup> *See id.*

<sup>33</sup> *See id.*

<sup>34</sup> *See* Kevles & Berkowitz, *supra* note 14, at 242.

<sup>35</sup> *Id.*

<sup>36</sup> *See id.*

<sup>37</sup> *See id.*

<sup>38</sup> *See* Laura M. Beskow, *Lessons from HeLa Cells: The Ethics and Policy of Biospecimens*, 17 ANN. REV. GENOME HUM. GENETICS 395, 397 (2016).

<sup>39</sup> *See id.*

<sup>40</sup> *See id.*

Nevertheless, the story of the HeLa cells highlights ongoing and intensifying questions about the use of human biospecimens in research. There's an urgent need for policy reforms that align with living ethical standards and meet the challenges posed by advancements in genomic and big-data science. Key considerations include ensuring public input on acceptable research practices, emphasizing the recognition and respect of every individual, maintaining public and patient trust, facilitating research aimed at reducing suffering and enhancing human health, and upholding the moral responsibility to ensure that the benefits of such research are universally accessible.<sup>41</sup>

#### IV. Conclusion

The ethical debate surrounding genetic patents is complex, touching on issues of consent, scientific innovation, donor rights, and religious beliefs. The story of Henrietta Lacks has been instrumental in shaping current policies and ethical standards, yet challenges persist. As science progresses, it is imperative that ethical frameworks continue to evolve to ensure the rights and dignity of individuals are safeguarded.

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<sup>41</sup> See *id.* at 408; see also *id.* at 411.