

Stealing What's Free: Exploring Compensation to Body Parts Sources for Their Contribution to Profitable Biomedical Research

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# Stealing What's Free: Exploring Compensation to Body Parts Sources for Their Contribution to Profitable Biomedical Research<sup>1</sup>

## Introduction

The great tragedy of Science—the slaying of a beautiful hypothesis by an ugly fact.

—T.H. Huxley, *Biogenesis and Abiogenesis*

At first blush, body parts donated in the name of science appears to be the beautiful solution to the problem of scarce body parts for research advancements. But a closer investigation reveals an ugly fact: the philanthropic donors—referred to as “Sources” in this article—are subjected to physical and financial exploitation.

Sources play a crucial and indispensable role in biotechnology. Without human body parts, most medical discoveries would not have been possible. Handsome profits can be derived from successful discoveries. But currently in the United States, when a Source provides body parts for research purposes, the researcher, research foundation, and outside investors are only a few of the parties who may claim a financial stake in the profits of this research. The Source is the only party who is excluded from being financially compensated for his contribution.<sup>2</sup> Despite being key player for ground-breaking medical discoveries, legal and political rhetoric block Sources from rightful compensation.

In this article, “Source compensation” will refer to a proportionate share of the research profits set aside for the Source as a result of his contribution. Today, Source compensation is prohibited. Laws are slow in reacting to technological change and resulting societal needs. The progress of Source compensation is hampered by stubborn, archaic attitudes about the value of the human body. However, this article will address the subtle movements in the law toward

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<sup>1</sup> Many thanks to Professor Elizabeth A. Rowe, for her insight, input, and intuition.

<sup>2</sup> John A. Sten, Comment, *Rethinking the National Organ Transplant Program: When Push Comes to Shove*, 11 J. Contemp. Health & Pol’y 197, 200 (1994).

Source compensation and the Constitutional soundness of this practice. Furthermore, public policy discussions, ethical implications, and comparisons with other socially embraced practices will highlight variations on Source compensation are already prevalent in society, and demonstrate that the concept is not so foreign after all.

### **The Uphill Battle: Source Compensation and the Law**

#### The Common Law Analysis

##### History

“The law marches with medicine, but in the rear and limping a little.”<sup>3</sup> This reflection illustrates a struggle to move forward in unison, due to a judicial system that is slow to resolve issues compared with the swift developments made in biotechnology. The law lags behind for a number of reasons. First, unlike areas such as tort law or commercial law, there is no field of law specifically focused on human biological materials or medical advances.<sup>4</sup> Instead, biotechnology and medical lawsuits rely upon a mosaic of related fields. Second, common law waits for an issue to ripen and for parties to gain standing before reflecting upon past injuries, and many issues in biotechnology introduce possibilities that have never before even been imagined. Third, it is entirely possible that biotechnology disputes could be rendered moot by the time the issues are resolved, due to the time disparity between the lengthy legal process compared to the speed at which the latest medical findings become obsolete. While common law must be credited with gaining some ground in biotechnology, its journey in the direction toward Source compensation is just beginning.

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<sup>3</sup> Symposium, *Medical Science, Moral Controversy, & Legal Change*, 64 Neb. L. Rev. 548 (1985).

<sup>4</sup> U.S. Congress, Office of Technology Assessment, *New Developments in Biotechnology: Ownership of Human Tissues and Cells—Special Report*, OTA-BA-337, at Ch.1 pg. 9 (Washington, DC: U.S. Government Printing Office, March 1987).

The following case studies illustrate three issues central to the debate over Source compensation: 1) informed consent, 2) profit potentials concealed from Sources, and 3) personal autonomy in body parts.

### The “Informed Consent” Hurdle

The catalyst initiating any medical procedure is informed consent. A physician has the expertise essential in evaluating risks and benefits of proceeding or abstaining from treatment. In contrast, while lacking medical expertise, the patient has the prerogative to determine the course of treatment, if any.<sup>5</sup> That is, the patient has a “right of self-decision” when consenting to treatment.<sup>6</sup> It is the physician’s duty to disclose all material information, such that the patient is empowered to make an intelligent decision regarding his own health.<sup>7</sup> Thus, the patient has a blind trust for his physician, by virtue of medical knowledge, which gives rise to a fiduciary physician-patient relationship.<sup>8</sup> An accepted standard for measuring the adequacy of the informed consent is the objective test: whether a prudent person in the same situation, who had been informed of all relevant risks and benefits, would have done as the patient did.<sup>9</sup>

Traditionally, informed consent referred only to medical treatment. However, the landmark case of *Moore v. Regents of the University of California* extends the definition to require that physicians “disclose personal interests unrelated to the patient’s health, whether research or economic, that may affect [the physician’s] judgment.”<sup>10</sup> Yet, despite demanding a patient’s informed consent, *Moore* illustrated the judiciary’s reluctance to compensate a Source for a contribution which ultimately yielded tremendous profits.

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<sup>5</sup> *Cobbs v. Grant*, 8 Cal. 3d 229, 242 (Cal. 1972)

<sup>6</sup> *Id.* at 245.

<sup>7</sup> *Id.* at 243.

<sup>8</sup> *Moore v. Regents of the Univ. of California*, 793 P.2d 479, 483 (Cal. 1990).

<sup>9</sup> *Canterbury v. Spence*, 464 F.2d 772, 791 (D.C. Cir. 1972).

<sup>10</sup> *Moore*, 793 P.2d at 485.

John Moore of California was diagnosed with leukemia in 1976. His physician, Dr. Golde, told Moore that his life depended on a splenectomy.<sup>11</sup> For seven years, Moore continued to receive Golde's treatments, including numerous extractions of blood, tissue, and body fluids. Golde insisted that these procedures were "necessary and required for [Moore's] health and well-being, and [Moore continued these visits] based upon the trust inherent in and by virtue of the physician-patient relationship."<sup>12</sup> Unbeknownst to Moore, these "treatments" had no relationship to treating his condition. Instead, Golde and his associates had an ulterior motive for collecting the body parts: Moore's cells had very rare qualities with enormous financial potential. These researchers secured for themselves the exclusive and unlimited access to these cells by exploiting Moore's fiduciary physician-patient relationship with Golde. The fruits of Golde's research yielded a patent on a cell line derived from Moore's body parts. Moore was not informed of his role in the development of this profitable, cutting-edge product, much less compensated for such. Ultimately, the patented cell line earned over \$440,000 and 75,000 shares of common stock in a biotechnology company for Golde and his associates.<sup>13</sup>

Because Moore had no property rights to his body parts under the law, the court refused to recognize his conversion claim as actionable.<sup>14</sup> Thus, while the *Moore* court recognized that Golde breached a fiduciary duty to Moore by failing to provide informed consent regarding the purpose of performing the extractions, the court refused to offer Moore any financial redress.<sup>15</sup>

This holding has a significant impact in the progress of biotechnology. No longer can physicians abuse their position of trust to remove body parts—under the guise of providing treatment—to fulfill their own scientific purposes. Sources must be provided with all material

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<sup>11</sup> Surgical procedure where the spleen is removed.

<sup>12</sup> *Moore*, at 481.

<sup>13</sup> *Id.* at 482.

<sup>14</sup> *Id.* at 497.

<sup>15</sup> *Id.* at 485, 497.

information regarding the fate of their body parts, and then choose to give informed consent to have their body parts used for those limited purposes.<sup>16</sup> Furthermore, the scientist's full disclosure gives Sources an opportunity to learn about the value of their bodies, and the significance of their impact on biotechnology. Appreciation of their own bargaining power is the first step in Source compensation.

Nonetheless, *Moore's* informed consent still has loopholes. Most significant is that a researcher needs only disclose that he intends to perform experiments on the Source's body parts,<sup>17</sup> not that the research product could yield financial profit. Thus, while the Source is empowered with the present value of his body, he is still ignorant of the potential value, and blind to the possible wealth a few of his cells may earn for the researcher. Furthermore, despite other jurisdictions' support of *Moore*,<sup>18</sup> courts in other jurisdictions continue to take steps backward since the *Moore* decision, dismissing Sources' attempts to integrate research intentions into informed consent.<sup>19</sup>

#### The "Fraudulent Concealment" Hurdle

While withholding medical knowledge constitutes a breach of fiduciary duty, withholding financial knowledge as it pertains to the profits of research can constitute fraudulent concealment. However, as evidenced in *Greenberg v. Miami Children's Hospital Research Institute, Inc.*,<sup>20</sup> to state an enforceable fraudulent concealment action, there are specific standards to overcome.

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<sup>16</sup> *Id.* at 497.

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

<sup>18</sup> *See, e.g.,* *Grimes v. Kennedy Krieger Inst.*, 782 A.2d 807 (Md. 2001); *In re Cincinnati Radiation Litig.*, 874 F. Supp. 796 (S.D. Ohio 1995).

<sup>19</sup> *See, e.g.,* *Hecht v. Kaplan*, 221 A.D.2d 100 (N.Y. App. Div., 1996).

<sup>20</sup> *Greenberg v. Miami Children's Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1067 (S.D. Fla. 2003).

In *Greenberg*, eight Florida parents had children suffering from Canavan disease, a rare and fatal hereditary disorder. They sought Dr. Matalon to discover the genetic cause. The parents provided Matalon with blood and tissue samples “for the specific purpose of researching Canavan disease,” with the understanding that “Matalon’s research would remain in the public domain to promote the discovery of more effective prevention techniques and treatments and, eventually, to effectuate a cure.”<sup>21</sup> By 1993, Matalon and his associates identified the gene responsible for Canavan disease.<sup>22</sup> In 1997, Matalon patented his work, granting him exclusive access to the Canavan gene and all its related testing, therapy, and research.<sup>23</sup> The parents did not learn of the patent until 1998, after Matalon had already received over \$75,000 in royalties.<sup>24</sup>

Fraudulent concealment is actionable under Florida law. The court reasoned that fraudulent concealment is enforceable only when heightened standards are satisfied.<sup>25</sup> Specifically, not only does the Source bear the burden of proving the elements,<sup>26</sup> but the Source must also state the circumstances of the fraud with particularity according to Fed. R. Civ. P. 9(b); that is, the “who, what, when, where, and how.”<sup>27</sup> Thus, although the parents argued that they would not have made their contributions if Matalon disclosed his intent to commercialize their body parts for his own financial benefit, the *Greenberg* court refused to recognize their fraudulent concealment action because the parents could not satisfy the heightened threshold.<sup>28</sup>

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<sup>21</sup> *Id.* at 1067.

<sup>22</sup> *Id.*

<sup>23</sup> *Id.*

<sup>24</sup> *Id.* at 1067-68.

<sup>25</sup> *Id.*

<sup>26</sup> *Jones v. General Motors Corp.*, 24 F. Supp. 2d 1335, 1339 (M.D. Fla. 1998) (defining fraudulent concealment as a misrepresentation of a material fact or suppression of the truth that induced detrimental reliance, and the fact was one which the representor a) knew was false, b) was unsure whether the fact is true or false, or c) ought to have known was false).

<sup>27</sup> *DiLeo v. Ernst & Young*, 901 F.2d 624, 627 (7th Cir. 1990).

<sup>28</sup> *Greenberg*, 264 F.Supp. 2d. at 1074.

*Greenberg* places an unreasonable burden upon the Source. The Source is already at a disadvantage due to the lack of scientific education, as recognized by jurisdictions demanding informed consent. Fraudulent concealment in the biotechnology context is different from other fraudulent claims in that the researcher may be the only one with the specific, technical knowledge to understand the particulars of the fraud. This unreasonably high threshold sets a dangerous precedent: a scientist may intentionally withhold disclosure of his use of body parts for his own financial gain, despite knowledge of the Sources' wishes to the contrary, and the court will dismiss the fraudulent concealment claim.<sup>29</sup>

#### The "Autonomy Over One's Body" Hurdle

The fraudulent concealment claim is not the only carrot on a stick for Sources; other potential claims can be just as difficult to justify. For example, in some states, Sources cannot argue unjust enrichment, a contractual inequity, because body parts are not formally recognized as property that can be exchanged for consideration.<sup>30</sup> In fact, much of the difficulty stems from the debate over whether Sources can be granted property rights in their bodies. While there is no distinct area of law focused on human biological materials or medical advances to resolve this issue, the other fields of law have successfully argued to provide Sources with relief. For example, in *Hecht v. Superior Court*,<sup>31</sup> the court deferred to property law and estate law to determine that sperm should be described as property and allowed its devise according to the deceased's will.

In *Hecht*, 48 year-old William Kane wished to bear another child with his girlfriend, Deborah Hecht. In 1991, Kane wrote a letter to be read after his death:

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<sup>29</sup> *Id.*

<sup>30</sup> *See, e.g.*, Conn. Gen. Stat. Ann. § 19(a)-280 (West 1990); VA. CODE ANN. § 32.1-289.1 (1985).

<sup>31</sup> *Hecht v. Superior Court*, 59 Cal. Rptr. 2d 222 (Cal. Ct. App. 1996).

I address this to my children, because, although I have only two . . . it may be that Deborah will decide—as I hope she will—to have a child by me after my death. I’ve been assiduously generating frozen sperm samples for that eventuality.<sup>32</sup>

Kane died a few weeks after this letter was written, and Hecht sought to become pregnant with the sperm left to her. Kane’s adult children challenged the will, demanding that all 15 vials of sperm be destroyed. They argued that preventing posthumous children is essential to preserving the family unit.<sup>33</sup> Contrary to overwhelming case law specifically refusing to grant property rights to body parts,<sup>34</sup> the *Hecht* court described sperm as “the seed of life . . . tied to the fundamental liberty of a human being to conceive or not to conceive. . . . [T]he fate of the sperm must be decided by the person from whom it is drawn.”<sup>35</sup> In essence, the court granted Kane a power of autonomy over his body parts to devise to whom he chooses, and further granted Hecht a limited property right to use the sperm only as Kane intended.

In addition to the progress made towards property recognition in body parts, *Hecht* is a crucial decision for proponents of Source compensation, because it enforces a Source’s right to make choices about his body parts: to whom they would belong, for what purpose they would serve, and the circumstances surrounding their destiny.

In the spirit of *Hecht*, some courts reached as far as treating pre-embryonic cells as property in disposition disputes, although not specifically granting “property” status.<sup>36</sup> It is notable that these cases all deal with reproductive cells, which, by virtue of their potential as “the seed of life,”<sup>37</sup> have more significant personal value to the Source than other cells or body parts.

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<sup>32</sup> *Id.* at 224.

<sup>33</sup> *Hecht v. Superior Court*, 20 Cal. Rptr. 2d 275, 279 (Cal. Ct. App. 1993).

<sup>34</sup> *See, e.g., Moore*, 793 P.2d 479; *Greenberg*, 264 F. Supp. 2d 1064; *Miles v. Scripps Clinic & Research Found.*, 810 F.Supp. 1091 (S.D. Cal. 1993).

<sup>35</sup> *Hecht*, 59 Cal. Rptr. at 226.

<sup>36</sup> *See, e.g., Davis v. Davis*, 842 S.W.2d 588 (Tenn. 1992); *Kass v. Kass*, 673 N.Y.S.2d 350 (N.Y. 1998).

<sup>37</sup> *Shapiro & Sonnenblick, The Widow and the Sperm: The Law of Post-Mortem Insemination*, 1 J. Law and Health 229, 232 (1983).

Accordingly, other body parts with presumably less sentimental attachment, such as skin or bone, should likewise be treated as property.

Seeking “property” status in one’s body is, however, not material to Source compensation. Rather, regardless of property status, Sources should be able to choose the fate of their body parts and, as a corollary, be compensated for their choices, if they so decide.

### The Statutory Analysis

Because common law authority in biotechnology has been generally uncharted territory, legislative enactments have attempted to shape permissible and prohibited activity, albeit in a direction away from Source compensation. Directed at issues regarding exchange of organs for transplants or medical research, Congress passed two acts: the National Organ Transplantation Act (NOTA) and the Uniform Anatomical Gift Act (UAGA).

#### The National Organ Transplantation Act

In 1984, Congress passed NOTA,<sup>38</sup> prohibiting the sale of organs for transplantation purposes.<sup>39</sup> Specifically, NOTA imposes a \$50,000 maximum fine and/or imprisonment up to five years for the buying and selling of all human organs “for valuable consideration for use in human transplantation if the transfer affects interstate commerce.”<sup>40</sup>

Although initially enacted to prevent a commercial market for organs,<sup>41</sup> where movements toward Source compensation are concerned, NOTA is not as difficult an obstacle to overcome as the common law has proven to be. First, NOTA applies only to organs, and makes no reference to cells, tissues, or fluids. Second, NOTA applies only to transplants—no reference is made to body parts used for research purposes. Thus, it is conceivable that financial

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<sup>38</sup> Pub. L. No. 98-507, 98 Stat. 2339 (1984) (codified as amended at 42 U.S.C. §§ 201, 273, 274e (Supp. 1994).

<sup>39</sup> See 42 U.S.C.S. § 274e(a) (Supp. 1994).

<sup>40</sup> *Id.*

<sup>41</sup> Lloyd R. Cohen, *Organ Transplant Market Would Save Lives*, Nat’l L.J., Jan. 29, 1996, at A19.

compensation for human cells, tissues, or fluids for research purposes is permissible under NOTA. However, a third, and a most troubling short-coming of NOTA, is an exception to the interstate commerce prohibition. Organ transplants are not to significantly affect interstate commerce; however, this prohibition does not apply to “payments associated with removal, transportation, implantation, processing, preservation, quality control, and storage of a human organ or the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with donation of the organ.”<sup>42</sup> Essentially, this NOTA exception applies to everyone but the Source, meaning that all parties involved in the transaction—even those performing medically unrelated tasks—may be financially compensated, except for the Source. Regardless of whether legislatures unintentionally left out Sources’ interests, NOTA unfairly prevents equitable compensation to Sources for their contributions.

#### The Uniform Anatomical Gift Act

By 1973, UAGA was adopted by all fifty states.<sup>43</sup> It provides that an individual of sound mind and at least eighteen years of age may donate his organs upon death.<sup>44</sup> In 1987, UAGA was amended to expressly prohibit the sale or purchase of a body part for transplantation or therapy.<sup>45</sup> Conceivably, the sale or purchase of body parts could be permissible if done for research. Again, UAGA’s applicability to Source compensation may be limited. Mainly, since Sources would likely be making *inter vivos* transfers, UAGA would not require body parts to be donated.

Thus, while Congress has attempted to alleviate problems between Sources and researchers, their enactments need significant updating to meet new research demands.

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<sup>42</sup> 42 U.S.C. § 274e(c)(2) (1994).

<sup>43</sup> Lloyd R. Cohen, *supra*.

<sup>44</sup> Unif. Anatomical Gift Act §2(a) (amended 1987), 8A U.L.A. 99 (1968).

<sup>45</sup> 1987 UAGA § 10(a), 8A U.L.A. 25 (Supp. 1990).

Currently, Sources have some leeway to interpret NOTA and UAGA as favoring Source compensation, as discussed. However, due to the vagueness of enforceable rights as outlined in case law, the legislature must recognize financial disparities between researchers and Sources, and protect Sources from this inequity.

### The Constitutional Analysis

There is, of course, no specific “right to Source compensation” in the U.S. Constitution. However, simply because a right is not expressly enumerated, it does not mean that this right is not constitutionally protected.<sup>46</sup> As described in the landmark *Griswold v. Connecticut*, “specific guarantees in the Bill of Rights have penumbras, formed by emanations from those guarantees that help give them life and substance.”<sup>47</sup> In other words, while the Constitution specifically outlines citizens’ rights, a penumbra is a broadened interpretation of the Constitution applied in the context of people’s lives. It is this penumbra that brings rights to life. Under the penumbra of the Fourth Amendment,<sup>48</sup> *Griswold* identified guaranteed zones of privacy.<sup>49</sup> As a fundamental liberty, the right to privacy is considered a right implicit in the concept of ordered liberty under the Due Process Clause of the Fourteenth Amendment<sup>50</sup>, and is offered the highest protection.

The penumbral right to privacy has been interpreted to mean a right to personal autonomy. Just as the issue in *Roe v. Wade*<sup>51</sup> was not the right to have an abortion, Sources do not argue that they have a right to be compensated. In *Roe*, a woman successfully challenged a statute prohibiting her from having an abortion on grounds that the statute invaded her privacy.

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<sup>46</sup> See, e.g., *Griswold v. Connecticut*, 381 U.S. 479 (1965).

<sup>47</sup> *Id.*, (finding unconstitutional a state statute prohibiting a physician from prescribing contraceptives to a married woman, as the governmental intrusion encroached on her rights to privacy).

<sup>48</sup> U.S. Const. amend. XIV (preventing warrantless governmental intrusions upon one’s home and person).

<sup>49</sup> *Griswold*, at 484.

<sup>50</sup> U.S. Const. amend. XIV.

<sup>51</sup> *Roe v. Wade*, 410 U.S. 113 (1973).

She did not argue her right to have an abortion; instead, she argued that under the penumbra of her fundamental right to privacy, she should be able to have the procedure done without governmental interference.<sup>52</sup> The Supreme Court agreed.<sup>53</sup> Therefore, the right to privacy must not be confused with the right to conduct the named activity. Rather, while there may be no specifically enumerated *right* to engage in this activity, penumbral protection is conferred upon the *privacy to engage* in this activity. It is also worthy to note that although Source compensation has raised considerable controversy among opponents, it pales in comparison to the magnitude of controversy and publicity concerning abortion. Logically then, the penumbra of privacy protecting abortion decisions from governmental intrusion should also extend to Source compensation. As privacy is recognized as a fundamental right, opponents would thus be challenged with overcoming the strict scrutiny of the courts.

Furthermore, under the Fourteenth Amendment, the Contracts Clause prevents legislative acts from impairing the contractual relationship between parties, unless a sufficient governmental interest can be shown.<sup>54</sup> Thus, between *Griswold* and *Roe* and their progeny, combined with the Contracts Clause, Sources have constitutional rights to be free from governmental intrusions into their private activities, and into their rights to contract. In other words, Sources should have the same penumbral right to privacy and to personal autonomy to enter into contractual relationships to exchange body parts for consideration without governmental intrusion. Prohibitions restricting the freedom to contract, as guaranteed by the Due Process Clause of the Fourteenth Amendment are subject to the lowest level of scrutiny—as long as the government has a legitimate objective which bears a rational relationship to the means chosen to achieve that goal, that prohibition will be upheld.

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<sup>52</sup> *Id.*

<sup>53</sup> *Id.*

<sup>54</sup> *Trustees of Dartmouth College v. Woodward*, 17 U.S. (4 Wheat) 518, 643 (1819).

While the government may oppose transactions involving body parts in exchange for consideration by arguing that it has an interest in guarding the health of the public, it is the researchers' and physicians' conduct that should be regulated, not that of the Source. For instance, the quality of the scientist's disclosure to potential Sources should be evaluated for quality and adherence to standard protocol. Regulating the disclosure scientists must give and prohibiting concealment of material information from Sources would account for guarding the health of the public, who have the right of privacy to choose a plan of action in their own best interest. Another example would be in imposing greater accountability upon scientists to maintain accurate records of whose body parts contributed to which discoveries. As will be discussed *infra*, the administrative demand upon scientists is no more demanding than those already encountered on a regular basis. In addition, researchers and physicians are the ones with extensive knowledge of their experiments and the consequences of participation, so the government should hold them to a higher standard of conduct. The Source, lacking the specialized education and inside information about the experiments, is in a more vulnerable position. In guarding the health of the public, the government further ought to protect Sources from scientists who do not adhere to proper disclosure protocol.

The government may further oppose Source compensation under the guise of protecting the morals of society. However, while the Constitution protects the interests of the public, it should neither dictate nor enforce the public's morals or beliefs.<sup>55</sup> Moreover, there has been backlash against laws promoting social morals. For example, in 1998, a U.S. Commissioner declared that the Patent and Trademark Office would reject biotechnology patents that were

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<sup>55</sup> Cooper v. Aaron, 358 U.S. 1, 24-25 (1958) (holding that "the Constitution is not the formulation of the merely personal views of the members of this Court, nor can its authority be reduced to the claim that state officials are its controlling interpreters.").

“injurious to the well-being, good policy, or good morals of society.”<sup>56</sup> Not only was the Commissioner attacked for presuming authority to enforce such prohibitions, but the statement launched public outcry against prohibitions on biotechnology grounded on moral arguments.<sup>57</sup>

Source compensation is a practice that should be afforded the highest constitutional protection as a fundamental right of privacy, in addition to constitutionally protecting Sources’ right to contract as guaranteed by the Fourteenth Amendment and the Due Process Clause. Furthermore, the government guards the interests of its citizens by supporting and enforcing Source compensation.

### **The Value of Body Parts**

Biotechnology in the United States is a multi-billion dollar industry.<sup>58</sup> In recent years, disagreements arise as to the exact numbers, but to place the value in context, in 1984, periodicals in the biotechnology industry predicted a potential market for a specific type of white blood cells at over \$3 billion dollars by 1990.<sup>59</sup> Another example reflecting the magnitude of wealth invested in biotechnology is the National budget. The National Institute of Health (NIH) is but one of seven agencies controlled by the Department of Health and Human Services.<sup>60</sup> Yet in 2004, the President’s budget for the NIH was \$27.9 billion.<sup>61</sup> Considering the numerous fields of research, most of which being associated with public, private, and corporate contributions, biotechnology can be considered one of the most profitable industries. That is, except for Sources who, under current law, legislative acts, and practices, are not being fairly compensated for their contribution.

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<sup>56</sup> Meredith Wadman, . . . *As U.S. Office Claims Right to Rule on Morality*, 393 *Nature* 200 (1998).

<sup>57</sup> David Dickson, *Legal Fight Looms Over Patent Bid on Human/Animal Chimeras*, 392 *Nature* 423 (1998).

<sup>58</sup> William Boulier, *Sperm, Spleens, and Other Valuables: The Need to Recognize Property Rights in Human Body Parts*, 23 *Hofstra L. Rev.* 693, 694 (1995).

<sup>59</sup> *Moore*, 793 P.2d at 482.

<sup>60</sup> U.S. Department of Health and Human Services, National Institute of Health, at <http://nih.gov/aboutNHI/NHIoverview> (last visited Mar. 20, 2004).

<sup>61</sup> National Institutes of Health, *Summary of the FY 2004 President’s Budget* (Feb. 3, 2003).

The public's ignorance as to the value of the human body in research allows Sources to be financially and physically exploited. Body parts have value to the scientific community both as a tool to conduct research, and financially, as the final product of the research. For the public to understand the value of human parts in medical research, they must first appreciate the crucial role body parts plays in biotechnology: without body parts from Sources, most medical progress would be severely hampered, if progression occurs at all. In 1987, 49% of researchers at medical institutions depended on Source body parts in their work.<sup>62</sup> Until it becomes possible to manufacture body parts in artificial laboratory settings, human Sources are a dire necessity.

Ignorant of their enormous bargaining power, Sources generally donate, trusting that their body parts are a gift to be used to better mankind. However, this trust in researchers and doctors could ultimately break down if Sources were to learn that these scientists turn around and profit from these gifts. A case in point is blood banks, where Sources give blood without compensation. Blood banks are then permitted to sell the blood to hospitals and research facilities for a profit, under the guise of either "selling a service" or "compensating the clinic for costs."<sup>63</sup>

Another obstacle preventing public appreciation for the value of human body parts in medical research is the propagated belief that body parts should only be afforded dignitary value, rather than commercial value. While it is a respectable view, it is also an archaic position. As society, technology, and the human condition progress, notions of acceptable and unacceptable practices are challenged. For instance, surrogate motherhood today is a common option that is

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<sup>62</sup> U.S. Congress, Office of Technology Assessment, *supra*, at Ch.1 pg. 8.

<sup>63</sup> See, e.g., Conn. Gen. Stat. Ann. § 19(a)-280 (West 1997); Del. Gen. Stat. Ann.. tit. 6, § 2-316(5) (2000); Fla. Stat. Ann. § 672.316(5) (West 2002)

gaining acceptance, while such an avenue was shunned, or considered a last resort just a few decades ago.<sup>64</sup>

Similarly, Source compensation is a budding issue pressing for resolution. Scandalous incidents over recent decades herald the inevitable: body parts can command a huge price tag. For example, college students are commonly compensated financially for providing both regenerative<sup>65</sup> and non-regenerative<sup>66</sup> body parts. In 2004, the University of California at Los Angeles became entangled in a legal web for allegedly selling donated cadavers to prominent pharmaceutical companies.<sup>67</sup> Finally, and most horrifying, are the overseas reports of organs being stolen from the living to be sold on the international black market.<sup>68</sup>

These examples clearly repudiate the notion that body parts are of no value. Evidently, biotechnology has transformed the traditional notions of the body “from merely a source of labor, or food for worms, to a highly prized biological commodity.”<sup>69</sup> If anything, allowing compensation for a valuable contribution validates the Source’s dignity by giving him an enforceable stake in the research.<sup>70</sup> Nonetheless, the public’s perception of the human body’s commercial value is but one obstacle to overcome in securing compensation for Sources. Not

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<sup>64</sup> See, e.g., Iris Leibowitz-Dori, *Womb for Rent: The Future of International Trade in Surrogacy*, 6 Minn. J. Global Trade, 329, 341 (1997) (commenting on the growing popularity of surrogacy as its publicity increases); see also, Lisa L. Behm, *Legal, Moral, & International Perspectives on Surrogate Motherhood*, 2 DePaul J. Health Care L. 557, 558 (1999); Christine L. Kerian, *Surrogacy: A Last Resort Alternative for Infertile Women, or a Commodification of Women’s Bodies and Children?*, 12 Wis. Women’s L.J. 113, 116 (1997).

<sup>65</sup> See, e.g., Kenneth Baum, *Golden Eggs: Towards the Rational Regulation of Oocyte Donation*, 2001 B.Y.U. L. Rev. 107 (2001) (compensating college students for sperm and ova).

<sup>66</sup> Comment, *Tax Consequences of Transfers of Bodily Parts*, 73 Colum. L. Rev. 842, 845 n.21 (1973) (compensating college student for parts of thigh muscle).

<sup>67</sup> Robert Jablon, *Demand Spurs Virtually Unregulated Trade in Cadavers; UCLA Stops Accepting Bodies During Probe*, Mar. 10, 2004, at [http://www.boston.com/news/education/higher/articles/2004/03/11/scandal\\_at\\_ucla\\_reveals\\_cadaver\\_trade\\_as\\_big\\_business/](http://www.boston.com/news/education/higher/articles/2004/03/11/scandal_at_ucla_reveals_cadaver_trade_as_big_business/) (last visited April 24, 2006).

<sup>68</sup> See, e.g., Hugh O’Shaughnessy, *Murder and Mutilation Supply Human Organ Trade*, The Observer, Mar. 27, 1994, at 27 (disappearing Russian orphans); Charles P. Wallace, *For Sale: The Poor’s Body Parts*, L.A. Times, Aug. 27, 1992, at A1 (kidnapping for kidneys in India).

<sup>69</sup> Michale H. Scarmon, *Property Rights in the Human Body—Are the Goods Oft Interred with Their Bones*, 37 S.D. L. Rev. 429 (1992).

<sup>70</sup> William Boulier, 23 Hofstra L. Rev. at 719.

only does legislation fail to protect Sources, but because the government is the primary source of funding,<sup>71</sup> then indirectly, the government will continue to promote Source exploitation by supporting the biotechnology industry.

### **The Source Shareholder Solution**

Source compensation proponents have proposed a multitude of solutions. Pennsylvania has launched a pilot program to compensate the Source for reasonable funeral expenses upon his death.<sup>72</sup> Other supporters have suggested granting Sources official property rights in their bodies.<sup>73</sup> Still other proponents recommend offering tax incentives.<sup>74</sup> This article, however, proposes another solution.

The Source Shareholder solution attempts to combat the evils of exploitation from both sides: preventing Sources from demanding compensation from scientists whose research has not yet earned capital, and preventing scientists from ignoring the Sources' contribution. The Source Shareholder solution is modeled after the shareholder system used by corporations, and is intended to spread the wealth from the industry to all contributors, including Sources.

The mechanism of compensation is simple. After a researcher obtains the body part, the Source would retain a percent (or fraction of) interest in the researcher's final product. This interest would be akin to a share of stock. If the researcher's final product is profitable, that Source has the choice to either "cash in" his stock, thereby selling his interest back to the researcher, or to hold on to the interest, such that as profit presumably accrues over time, the Source's share would increase in value.

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<sup>71</sup> U.S. Congress, Office of Technology Assessment, *supra*, at 7.

<sup>72</sup> Laurel R. Siegel, *Re-engineering the Laws of Organ Transplantation*, 49 Emory L.J. 917 (2000).

<sup>73</sup> See, e.g., Roy Hardiman, 34 UCLA L. Rev. 207; Emily Denham Morris, *The Organ Trail: Express Versus Presumed Consent as Paths to Blaze in Solving a Critical Shortage*, 90 Ky. L.J. 1125 (2002); *Id.*

<sup>74</sup> See, e.g., Frederick R. Parker, Jr. et al., *Organ Procurement & Tax Policy*, 2 Hous. J. Health L. & Pol'y 173 (2002).

As a scientist's research progresses and more shares are needed for additional Sources, a stock-split can occur, thus ensuring earlier Sources will be proportionately compensated, while enabling newer Sources to be compensated as well.

The obstacles to this solution, of course, would be to gain legislative support for such a system. A system of good faith dealing would also be required between the researcher and the Source.<sup>75</sup> Moreover, Sources would need to be guarded against fraud and deception. However, building on established shareholder principles, and on practices already accepted in society that are similar to Source compensation, the Source Shareholder system could prove to be a successful means to compensate Sources proportional to their contribution, spread the wealth in technology to society, and avoid the evils of selling body parts.

### **Source Compensation: Public Policies and Ethical Issues**

#### No Exploitation of the Poor

Opponents of Source compensation are concerned with exploitation of the poor.<sup>76</sup> However, this would only occur if they were induced with rags-to-riches promises. Particularly with the Source Shareholder solution, this is not the case, for a number of reasons.

First, the amount of compensation will be dictated by market mechanisms of supply and demand. Until body parts can be manufactured in laboratories to meet educational, research, and transplant needs, the lucrative market for human body parts will continue. Offering financial incentives will increase the number of willing Sources. With the pressure of demand eased, Sources will bargain for less consideration in order to stay competitive. Thus, unless the Source

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<sup>75</sup> This system would prevent, for example, circumstances where Sources' shares are only worth pennies while the enormous profit still ends up in the researcher's pocket.

<sup>76</sup> See, e.g., Roy Hardiman, *Toward the Right of Commerciality: Recognizing Property Rights in the Commercial Value of Human Tissue*, 34 UCLA L. Rev. 207 (1986).

possessed a rare characteristic, he would not be in a position to bargain for unreasonably high figures.

Second, under this model of compensation, potential Sources are informed that there is a possibility that they will not be compensated at all, if the research is not profitable. In addition, it is likely that it would take a long time for a profitable scientific discovery to accumulate wealth. Therefore, even if impoverished Sources were to invest their body parts, presumably, they would sell their share soon after it becomes profitable to gain immediate reward. The prospect of long-term financial return, if any, thus serves to deter the poor from providing body parts for money. Compensation is meant to be just that—compensation is not a livelihood.

Third, it is unlikely that compensation received for body parts will create overnight millionaires. The premise of compensation is that Sources take only a share of profits, and it is proportionate to contribution. Thus, if the contribution is small, it could be reasonable for a Source to agree to only a fraction of a percent of the researcher's profits. While some biotechnology discoveries have become enormously profitable, most are only moderately so. Furthermore, it is entirely possible that the research is altogether fruitless—without the researcher profiting, the Source cannot profit either. This prospect will likely deter those dreaming of wealth by simply providing body parts. In fact, an advantage of this system is that it encourages education and public awareness of medical advances. Coupled with the researcher's full disclosure, a potential Source may decide that the venture is not promising enough to invest his body parts. Thus, Sources who educate themselves about biotechnology and research advances are the ones most likely to be compensated.

Fourth, it should be of little concern that substance abusers would resort to becoming a Source to generate income to support their habits. The obvious and unfortunate effect of

substance abuse is the self-destructive toll it takes on the body. Damaged or diseased body parts likely will have little value for research. Additionally, having already established many of the detrimental effects of substance abuse, the body parts of substance abusers likely will be unfit for any profitable use.

#### No Effect on Cost to the Consuming Public

Concerns regarding Source compensation increasing costs to the consuming public are also unfounded.<sup>77</sup> Again, the premise is that Source compensation is derived from post-consumer profits. Thus, normal increases in pre-consumer costs, for example, in marketing or transporting the product, would have larger effects on the public. Further, even Congress' reports state: "actual compensation to the human sources of original tissues and cells is unlikely to have a large economic impact on the use of human biological materials."<sup>78</sup>

Opponents also argue that because researchers often share work and findings, that having to compensate Sources would interfere with a "free" trade of information.<sup>79</sup> Further, they contend that if researchers were to share body parts or derivatives of body parts, keeping detailed records of Sources' origins to adequately compensate them would be unduly burdensome.<sup>80</sup> These concerns are exaggerations. Given, additional record-keeping will be inevitable to ensure Source compensation, but researchers already maintain meticulous records of medical histories and background information on Sources, in order to control their experiments for anomalous results.<sup>81</sup> Furthermore, the administrative effort for keeping track of whose body parts contributed to which products is no more demanding than the work physicians routinely encounter with respect to organizing insurance or alternative billing arrangements. As far as

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<sup>77</sup> See, e.g., U.S. Congress, Office of Technology Assessment, *supra*.

<sup>78</sup> See, *id.*, at Ch.1 pg. 13.

<sup>79</sup> *Id.*

<sup>80</sup> *Id.*

<sup>81</sup> See Roy Hardiman, 34 UCLA L. Rev. at 241.

interfering with the “free” trade of information, researchers often credit each other for providing equipment, tools, and other resources that required financial or intellectual investment. Body parts are no different, especially since the original researcher expends no finances to compensate the Source until a derivative product proves profitable. From there, patents guard fierce financial competition between researchers.

#### Strengthens Self-Concept and Physician-Patient Relationship

As discussed, the Source places confidence in the physician-patient relationship. Full disclosure of material information relevant to the treatment or research, including economic potential, is essential to the trust Sources place in their physician. For a doctor to be bound by Hippocratic Oath to disclose personal research interests that may conflict with his professional judgment strengthens the Source’s faith in the physician-patient relationship. Inherent in that disclosure is also potential risks to Sources, should they partake in research activities. Thus, it is ultimately up to the researcher or physician to prevent Sources from endangering their health. This judgment call is akin to those made in every physician-patient transaction. As such, a breach of this duty subjects the physician or researcher to sanctions.

Despite the informed consent requirements, Source compensation opponents posture that although not endangering health, society could be plagued with disfigured people who sought compensation.<sup>82</sup> This issue is unfounded and far-fetched. As discussed *supra*, compensation does not promise wealth; in fact, if the research proves fruitless, Sources will not be compensated at all. Thus, it is unlikely that society will be driven to disfigurement on those grounds. Also, this argument promotes the attitude that the disfigured or disabled are lesser individuals. There are a multitude of disabled or disfigured individuals who are contributing,

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<sup>82</sup> See, e.g., Michelle Bourianoff Bray, *Personalizing Personalty: Toward a Property Right in Human Bodies*, 69 Tex. L. Rev. 209 (1990).

productive members of society. For instance, despite losing a leg to cancer, Terry Fox ran over 3,300 miles in 143 days across Canada to raise money for cancer research before succumbing to the disease.<sup>83</sup> Other examples include members of the Association of Mouth and Foot Painting Artists (who, as the name suggests, create paintings by using only their mouth or foot because their hands are unable to do so<sup>84</sup>), and Erik Weihenmayer (who became the first blind person to climb Mt. Everest<sup>85</sup>). Loss of a physical body part cannot be equated with the loss of identity or self-worth. The suggestion that vanity-controlled self-esteem issues could result from Source compensation is no more than speculation and a superficial presumption that does not support a public policy argument.

#### The Protection of Individual Autonomy—The Fairness Argument

Permitting Sources to be compensated proportional to their contributions to science is consistent with traditional concepts of commercial fairness. It protects their individual autonomy by giving them an enforceable interest. Furthermore, it prevents a profitable industry, which still receives extraordinary financial support from the outside, from unjustly enriching themselves with the exclusive benefit of the Source's body parts. Scientists wrongfully persuade Sources from many angles to unconditionally provide body parts. For instance, Sources are often told that removal of harmful tissues or organs is in itself a form of compensation, and that the scientists should be able to keep the offending body part in consideration for its removal.<sup>86</sup> This scenario extends to experiments involving placebos, such that the Source may not be receiving much more than a sugar pill, whereas the researcher gains valuable scientific data.

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<sup>83</sup> The Terry Fox Foundation, at <http://www.terryfoxrun.org/english/about%20terry%20fox/default.asp?s=1> (last visited Apr. 24, 2006).

<sup>84</sup> AMFPA—Association of Mouth and Foot Painting Artists, at <http://www.aapbp.com/html/show.php?lang=2&mid=100&oid=943> (last visited Apr. 24, 2006).

<sup>85</sup> Prove Them Wrong, at [www.provethemwrong.com/weihenmayer.htm](http://www.provethemwrong.com/weihenmayer.htm) (last visited Apr. 24, 2006).

<sup>86</sup> See U.S. Congress, Office of Technology Assessment, *supra*, at Ch.1 pg. 12.

However, these persuasions confuse the “benefit of treatment” with the “benefit of being compensated for contributing to a profitable research project.”

Sources have also been told that replenishable body parts, such as blood, are useless to a Source once it has been extracted.<sup>87</sup> Despite the “uselessness” to the Source, that does not mean that the extraction is of no value. On one hand, if not for the scientist’s intervention, the body parts have no independent value, but on the other hand, if not for the Source’s contribution, the scientist would not have had the means to achieve his profitable results. Source compensation is not meant to drain financial resources from fledgling research projects. It seeks to dissolve the inequity of full reward to the researcher, while ignoring the Source’s contribution.

Thus, these positions are no more than arguments used to persuade the Source to give away their body parts—in essence, removing the Source’s bargaining power in an attempt to steal what is already free. Basically, by robbing body parts, researchers rob Sources of personal autonomy. Returning to *Hecht*, the court went further than simply recognition of Kane’s wishes to devise his sperm to his girlfriend; it recognized the autonomy to control the purpose of one’s body parts or choose the circumstances around their use. This decision recognizes and enforces rights critical to preserving personal autonomy over one’s body. Thus, regardless of the burden on the industry, it is a stronger policy interest to uphold equity and protect Sources from physical and financial exploitation.

### **Familiar Models in Society**

While Source compensation is not yet an available option, other accepted practices in society suggest that it could and should be adopted. For instance, employees in certain trades who lose body parts during the scope of employment often receive disability benefits through workers’ compensation plans. The loss or injury of a specific body part determines particular

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<sup>87</sup> *Id.*

payment schedules.<sup>88</sup> Thus, there is an objective appreciation that body parts have inherent economic value, and furthermore, that different body parts have different values. Since employment contracts are generally economic compensation in consideration for labor, workers' compensation recognizes the inequity of an employee putting his body at risk so an employer may continue to profit, and compensates employees for lost body parts in the line of duty. It places the economic burden of lost body parts on the party more capable of bearing that burden, and compensates the contribution (and at this point, the sacrifice) of the employee. The premise is similar to Source compensation in medical research, where the amount of compensation is determined by the body part's value to both the researcher and the Source. Additionally, under both workers' compensation and Source compensation, the economic benefit is not meant to create wealth.

The field of reproductive health has already established policies to compensate Sources for eggs, sperm, and even embryos, albeit not for the body parts per se. With the advent of reproductive technology becoming safer and more successful, couples who were previously unable to conceive have opened their pocketbooks to Sources for precious live-giving cells. Traditionally, female Sources providing eggs have been compensated between \$1,000 - \$5,000 for their inconvenience, but in 2001, reports of compensation of \$50,000 were not surprising.<sup>89</sup> Yet, in a similar context, male sources providing sperm are generally only compensated \$50.<sup>90</sup> Though economic value in these cases is not determined by profits derived from their body parts, Sources are at least compensated for the emotional value of the body parts.

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<sup>88</sup> See, e.g., Ariz. Rev. Stat. Ann. § 23-1044(b) (West Supp.1989); Colo. Rev. Stat. § 8-51-104 (1986); Pa. Stat. Ann. tit. 77, § 513(Purdon Supp. 1989).

<sup>89</sup> See generally, Kenneth Baum, 2001 B.Y.U. L. Rev. at 108-109.

<sup>90</sup> Interview with Evan E. Follas, General Manager of Follas Laboratories Inc., Indianapolis (Nov. 12, 1991).

The high price tag for providing life-giving cells is not limited to provision of gametes. In some states, surrogate mothers may be compensated for expenses beyond those related to pregnancy.<sup>91</sup> Similarly, private adoption<sup>92</sup> has recently gained acceptance. However, even then it is often difficult to distinguish between expense reimbursement and compensation unrelated to the pregnancy.<sup>93</sup> It would be naïve to believe that economic transactions were strictly limited to reimbursement; yet neither legislature nor the common law has distinguished between them, arguably because compensation to the birth mother has been deemed “equitable.”

The movement toward Source compensation is evident in the recent mimicking of surrogate compensation. Furthermore, in 2004, the White House overwhelmingly passed a bill to reimburse organ donors for travel and non-medical expenses.<sup>94</sup> Although the legislation is specifically for Sources providing body parts for transplant surgery, it is a reflection upon shifting governmental appreciation for the value of Sources in biotechnology.

Public and media opposition against Source compensation for non-reproductive body parts is small compared to opposition against compensation in more sensitive areas, such as reproductive body parts, use of body parts for gestation, or even adoption. Yet, there are a growing number of examples of compensation for these sensitive areas. It follows then, that if society and the law accepts compensation as equitable in these circumstances, then certainly where non-reproductive body parts are concerned, Source compensation should be accepted as well.

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<sup>91</sup> See *Johnson v. Calvert*, 851 P.2d 776 (Cal. 1993).

<sup>92</sup> Private adoption is where the birth mother is compensated for expenses incurred during the pregnancy, and payments to any intermediaries are limited to costs for professional services. Jana B. Singer, *The Privatization of Family Law*, 1992 Wis. L. Rev. 1443, 1483-84 (1992).

<sup>93</sup> See, e.g., James B. Boskey, *Placing Children for Adoption*, in *Adoption Law & Practice*, (Joan H. Hollinger ed. 1992), at p. 3-1, p. 3-6.

<sup>94</sup> Aparna H. Kumar, *House OKs Funding to Spur Organ Donations*, Mar. 24, 2004, at [http://www.signonsandiego.com/news/health/20040324-1116\\_organ donation.html](http://www.signonsandiego.com/news/health/20040324-1116_organ donation.html) (last visited Apr. 24, 2004).

## Conclusion

It is undisputed in the biotechnology industry that human body parts play a vital role in research. Forbidding the explosion of profits from trickling down to the Source presents an irrational inequity. Despite established law, it is evident from case analysis and prevailing social practices that Source compensation is a plausible solution. As long as Sources provide informed consent to have their body parts extracted for research purposes, compensating them for contributions to a profitable venture promotes faith in the physician-patient relationship and fosters individual autonomy. Furthermore, Sources have a right of privacy, and their compensation is a practice that should be protected under the Constitution.

While opponents cite reasons ranging from economics to ethics, the advantages of Source compensation outweigh the setbacks. Sources' financial rewards are likely miniscule compared to those of the scientist, assuming that there are profits to split at all. Additionally, the Source Shareholder solution minimizes public policy concerns by promoting Source education and preventing the exploitation of the poor.

Attitudes centered around vanity are exchanged for views that the human body is valuable, and has intrinsic economic worth. In the face of opposition, a slow-reacting judicial system, and persistent archaic attitudes, the future of Source compensation is uncertain, but recent governmental and societal progress is promising—"If there is no struggle, there is no progress."<sup>95</sup>

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<sup>95</sup> Frederick Douglass, Speech at Canandaigua, New York (Aug. 3, 1857).