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# Book Review: Body Banking from the Bench to the Bedside

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## BOOK REVIEW

### BODY BANKING FROM THE BENCH TO THE BEDSIDE

**BANKING ON THE BODY: THE MARKET IN BLOOD, MILK, AND SPERM IN MODERN AMERICA.** By Kara W. Swanson. Cambridge, Mass.: Harvard University Press. 2014. Pp. 333. \$35.00.

*Reviewed by Natalie Ram\**

How much is a kidney worth? An ounce of breast milk? Genetic material from an individual facing a Parkinson's diagnosis? In today's America, it depends on who is selling. One might think that such body products are beyond value or that their value depends on the individual characteristics of the supplier. But under existing American law and practices, what matters more is whether the seller is also the supplier of that body product, or whether the seller is another entity, such as a pharmaceutical company, hospital, or biobanker.<sup>1</sup>

Under existing American law, for instance, an individual may not sell her kidney for "valuable consideration."<sup>2</sup> Nor may an individual direct that her body be sold for profit to a medical school after her death.<sup>3</sup> Yet a medical school receiving such a donation is free subsequently to sell that body to a peer institution, in whole or in part (p. 245).<sup>4</sup>

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\* Assistant Professor, University of Baltimore School of Law; J.D., Yale Law School; A.B., Princeton University. Many thanks to Gregory Dolin, David Jaros, members of the UB/UM junior faculty workshop, and the participants of the Biobanking Eggs and Embryos for Research workshop for their helpful comments on this project. Thanks also to the editors of the *Harvard Law Review* for their insightful suggestions and corrections throughout the editing process. All errors are my own.

<sup>1</sup> The bioethics literature typically describes a research body bank as a "biobank," as it is a bank of biological specimens. Beyond this general definition, however, "[s]ignificant variation in biobank types [has left] scholars unable to agree upon a definition" of what exactly counts as a biobank. Gail E. Henderson et al., *Characterizing Biobank Organizations in the U.S.: Results from a National Survey*, *GENOME MED.*, Jan. 2013, art. 3, 2. In keeping with Swanson's language describing the medical "body bank," this Review refers to body banks for research purposes as "body banks" and "biobanks" interchangeably.

<sup>2</sup> National Organ Transplant Act § 301(a), 42 U.S.C. § 274e(a) (2012).

<sup>3</sup> See, e.g., REVISED UNIF. ANATOMICAL GIFT ACT § 4 (NAT'L CONFERENCE OF COMM'RS ON UNIF. STATE LAWS 2006) (providing instead that "an anatomical gift of a donor's body or part may be made during the life of the donor for the purpose of transplantation, therapy, research, or education").

<sup>4</sup> See also Bridget J. Crawford, *Our Bodies, Our (Tax) Selves*, 31 VA. TAX REV. 695, 709–10 (2012); David E. Harrington & Edward A. Sayre, *Paying for Bodies, but Not for Organs*, *REGULATION*, Winter 2006–2007, at 14, 14 ("[M]edical schools often have a surplus of cadavers while other institutions cannot find the tissues and body parts they need via markets. . . . One of the reasons for the glut of cadavers at medical schools is that most states allow government officials to donate unclaimed bodies to medical schools, often specifying which schools are eligible for the

A similar disparity in payment arises when human breast milk is at issue. Payments for breast milk are not illegal, but they are often frowned upon<sup>5</sup> — and where such payments do occur, they may stand in stark disparity to the payments received by others in the body-product supply chain. Consider, for instance, the business model of Prolacta Bioscience. Through a network of twelve national, regional, and local milk banks, Prolacta Bioscience encourages breastfeeding mothers to donate milk their own infants do not need.<sup>6</sup> Up until last year, Prolacta did not pay these women for their milk, assuring them that “[b]reast milk donors report a sense of satisfaction knowing they are providing their milk to help premature or sick infants.”<sup>7</sup> Indeed, a Prolacta-sponsored website continues to explain that “[t]he current practice in North America is to accept breast milk donations without compensating the mother.”<sup>8</sup> Even now, Prolacta and its affiliated milk banks offer payment of only up to one dollar per ounce of shipped breast milk — and they insist that this payment is merely an “expense reimbursement.”<sup>9</sup> Meanwhile, the milk banks “receive payment from

bodies.”); Stephanie Armour, *Donated Bodies Sometimes Are Sold for Personal Profit*, USA TODAY (Apr. 28, 2006, 12:56 AM), [http://usatoday30.usatoday.com/tech/science/2006-04-27-body-parts-sold\\_x.htm](http://usatoday30.usatoday.com/tech/science/2006-04-27-body-parts-sold_x.htm) [<http://perma.cc/5DGC-AEYY>] (noting that “Tulane University’s medical school received more cadaver donations than it could use,” and that it and other universities “typically share any surplus cadavers with other medical schools,” as well as with private research firms for a “processing fee”).

<sup>5</sup> See Robin Erb, *Detroit Moms Protest Breast Milk Banking Effort*, DETROIT FREE PRESS (Jan. 14, 2015, 10:34 AM), <http://www.freep.com/story/news/health/2015/01/13/breast-milk-bank-protest-detroit/21702019> [<http://perma.cc/4GP6-GDJW>].

<sup>6</sup> See PROLACTA BIOSCIENCE, <http://www.prolacta.com> [<http://perma.cc/UE9Q-JK2B>].

<sup>7</sup> Knowledge Center, PROLACTA BIOSCIENCE, <http://www.prolacta.com/knowledge-center> [<http://perma.cc/8N3G-TP8L>] (responding to the question: “Why should I donate?”); see also Andrew Pollack, *Breast Milk Becomes a Commodity, with Mothers Caught Up in Debate*, N.Y. TIMES (Mar. 20, 2015), <http://www.nytimes.com/2015/03/21/business/breast-milk-products-commercialization.html>.

<sup>8</sup> *Milk Banking Frequently Asked Questions*, MILKBANKING.NET, <http://www.milkbanking.net/faqs> [<http://perma.cc/7FJT-FRZ6>] (responding to the question: “Will I be paid for my donations?”). As recently as October 2014, Prolacta’s main website provided the same response. See Knowledge Center, PROLACTA BIOSCIENCE, <https://web.archive.org/web/20141027202142/http://www.prolacta.com/knowledge-center> (archived Oct. 27, 2014) (responding to the question: “Why doesn’t Prolacta pay mothers for their milk donations, but sells the end product?”).

<sup>9</sup> See, e.g., *Expense Reimbursement Terms and Conditions*, WESLEY MED. CTR., <http://www.wesley.prolacta.com/donate-breast-milk#reimbursement> [<http://perma.cc/F56H-RY2S>] (explaining that supplying mothers who register by a certain date and ship 300 ounces of human breast milk within an “initial qualification period (123 days from date of blood sample collection)” are eligible to receive \$300, but explaining further that “[e]ach donor can be eligible for only one reimbursement check for donations made through any Prolacta-affiliated donor milk program”); see also Carolina Buia, *The Booming Market for Breast Milk*, NEWSWEEK (May 23, 2015, 4:11 PM), <http://www.newsweek.com/booming-market-breast-milk-335151> [<http://perma.cc/7DEZ-D4LR>] (reporting that Prolacta and Medolac (another bioscience company) “pay their screened donors \$1 an ounce”).

Pro lacta Bioscience for the milk they collect.”<sup>10</sup> And having acquired human breast milk with little or no compensation to its supplying mothers, Pro lacta processes, fortifies, and sells that milk to hospital nurseries for as high as \$180 or more per ounce.<sup>11</sup>

This virtual exclusion of supplying bodies from the chain of compensation extends beyond medical treatment into the realm of medical research. In January 2015, 23andMe, a provider of direct-to-consumer genetic analysis, announced high-profile data-sharing arrangements through which multiple pharmaceutical companies will gain access to the full genetic profiles of thousands — and in some instances, hundreds of thousands — of 23andMe’s customers.<sup>12</sup> While the financial details of a deal 23andMe struck with Pfizer are unknown, another pharmaceutical company, Genentech, agreed to pay 23andMe ten million dollars upfront, with additional payments of up to fifty million dollars should the research prove good for business.<sup>13</sup> The ultimate providers of all that genetic information, however, will not be paid for the use of their genetic information.<sup>14</sup>

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<sup>10</sup> *Milk Banking Frequently Asked Questions*, *supra* note 8 (responding to the question: “Will I be paid for my donations?”).

<sup>11</sup> See Pollack, *supra* note 7; see also Linda C. Fentiman, *Marketing Mothers’ Milk: The Commodification of Breastfeeding and the New Markets for Breast Milk and Infant Formula*, 10 NEV. L.J. 29, 33 (2009); Ricardo Lopez, *Pro lacta Develops Niche Delivering Breast Milk to Hospitals*, L.A. TIMES (Oct. 25, 2013, 5:00 AM), <http://www.latimes.com/business/la-fi-breast-milk-processing-20131025-story.html> [<http://perma.cc/9KN4-BCTP>] (observing that a bottle of Pro lacta fortified milk “can cost \$125 to \$312, depending on the caloric formulation”). The price Pro lacta can charge for its fortified breast milk product reflects more than merely the price of the human breast milk alone. Pro lacta holds several patents “for standardized human milk products as well as for the production and use of these products,” and so can charge premium prices. *Our Intellectual Property*, PRO LACTA BIOSCIENCE, <http://www.prolacta.com/our-intellectual-property> [<http://perma.cc/XJL3-74HR>]; see also Thomas F. Cotter, *Patents, Antitrust, and the High Cost of Health Care*, ANTITRUST SOURCE, Apr. 2014, art. 2, at 2, [http://www.americanbar.org/content/dam/aba/publishing/antitrust\\_source/apr14\\_cotter\\_4-8f.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/publishing/antitrust_source/apr14_cotter_4-8f.authcheckdam.pdf) [<http://perma.cc/7Z4L-MLNP>] (noting that because patents confer monopoly rights and therefore market power, “it should not come as a big surprise when [the health care companies that own patents] charge prices that exceed marginal cost”).

<sup>12</sup> See Press Release, 23andMe, 23andMe Announces Collaboration with Pfizer Inc. to Conduct Genetic Research Through 23andMe’s Research Platform (Jan. 12, 2015), <http://mediacenter.23andme.com/blog/2015/01/12/23andme-pfizer-research-platform> [<http://perma.cc/Q2KL-5MXH>]; Press Release, 23andMe, 23andMe and Genentech to Analyze Genomic Data for Parkinson’s Disease (Jan. 6, 2015), <http://mediacenter.23andme.com/blog/2015/01/06/23andme-genentech-pd> [<http://perma.cc/4SGN-ACHM>]; see also Davey Alba, *23andMe Teams with Big Pharma to Find Treatments Hidden in Our DNA*, WIRED (Jan. 12, 2015, 4:31 PM), <http://www.wired.com/2015/01/23andme-partners-big-pharma-find-treatments-hidden-genes> [<http://perma.cc/659Z-VMCH>] (reporting that the agreement between 23andMe and Pfizer will grant Pfizer access to the genetic information of 650,000 of 23andMe’s customers).

<sup>13</sup> See Alba, *supra* note 12.

<sup>14</sup> Customers may, however, be paid “up to a value of \$30 per half hour of expected time” for answering survey or other questions about themselves. *Research Consent Document*, 23ANDME, <https://www.23andme.com/about/consent> [<https://perma.cc/DB3G-R6R7>].

Moreover, while 23andMe customers are permitted to broadly consent to or refuse participation in all “23andMe Research,” they have no ability to consent to some, but not all, research studies that might use their genetic information.<sup>15</sup> Indeed, as 23andMe enthusiastically notes, “[o]n average, a customer who consents to research contributes to over 230 studies.”<sup>16</sup> Still, these body-bank suppliers exercise more control over their genetic information than many. Often, in research settings, the sources of body products may not even have the opportunity to refuse participation, as their consent will never be sought.<sup>17</sup>

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<sup>15</sup> See *Research*, 23ANDME, <https://www.23andme.com/research> [<http://perma.cc/8NBV-7W5B>].

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

<sup>17</sup> Under existing federal human subjects research protections, so long as privacy is assured by de-identifying data or human biological specimens, researchers need not obtain consent to use such data or specimens. See *How Can Covered Entities Use and Disclose Protected Health Information for Research and Comply with the Privacy Rule?*, NAT’L INSTITUTES HEALTH, [http://privacyruleandresearch.nih.gov/pr\\_08.asp](http://privacyruleandresearch.nih.gov/pr_08.asp) (last updated Feb. 2, 2007) [<http://perma.cc/8Z2Q-2N3Z>]; see also 45 C.F.R. § 164.502(d) (2014); *id.* § 164.514(b)(2)(i) (enumerating eighteen identifiers, the removal of which renders what would otherwise be protected health information “de-identif[ed],” *id.* § 164.514(a), and outside the scope of the Privacy Rule of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of the U.S. Code)); OFFICE FOR HUMAN RESEARCH PROTS., U.S. DEP’T OF HEALTH & HUMAN SERVS., GUIDANCE ON RESEARCH INVOLVING CODED PRIVATE INFORMATION OR BIOLOGICAL SPECIMENS (2008), <http://www.hhs.gov/ohrp/policy/cdebiol.html> [<http://perma.cc/2V7C-38YU>] (reaffirming that the review and consent obligations ordinarily applicable to federally funded research do not apply to research using biological specimens that are not “individually identifiable”).

On September 2, 2015, sixteen federal agencies and departments, including the Department of Health and Human Services (HHS), released a notice of proposed rulemaking to amend and update the Common Rule, which governs most federally funded human subjects research (and all HHS-funded human subjects research). See Press Release, U.S. Dep’t of Health & Human Servs., HHS Announces Proposal to Update Rules Governing Research on Study Participants (Sept. 2, 2015), <http://www.hhs.gov/news/press/2015pres/09/20150902b.html> [<http://perma.cc/N42C-2N2S>]; Federal Policy for the Protection of Human Subjects, 80 Fed. Reg. 53,933 (proposed Sept. 8, 2015) (to be codified in scattered titles of the Code of Federal Regulations). Under the proposed rule, written consent will be required for secondary research using biological samples, regardless of de-identification or anonymization. Press Release, U.S. Dep’t of Health & Human Servs., *supra*; see also Federal Policy for the Protection of Human Subjects, 80 Fed. Reg. at 53,936 (summarizing major provision of the proposed rule); *id.* at 54,047 (setting out proposed section \_\_\_\_102(e) (blank in original) and defining “human subject” to include “a living individual about whom an investigator (whether professional or student) conducting research . . . [o]btains, uses, studies, or analyzes biospecimens”). However, such consent may be broad, applying to all future research projects, rather than permitting potential participants to consent to some research while refusing other research. See *id.* at 53,936 (“[I]nformed consent would generally be required for secondary research with a biospecimen (for example, part of a blood sample that is left over after being drawn for clinical purposes), even if the investigator is not being given information that would enable him or her to identify whose biospecimen it is. Such consent would not need to be obtained for each specific research use of the biospecimen, but rather could be obtained using a ‘broad’ consent form in which a person would give consent to future unspecified research uses.”); *id.* at 54,053–54 (setting out proposed section \_\_\_\_116(c), describing broad consent to secondary research of biospecimens). The proposed rule would not alter the HIPAA Privacy Rule standard for de-identification.

The cases of bodies and organs, breast milk, and genetic information are in many ways importantly distinct. They arise under significantly different legal regimes and social conventions.<sup>18</sup> They differently preclude or allow the body-product supplier to consent to the subsequent sale of their body parts to others.<sup>19</sup>

And yet treatment of each body product echoes a common theme and difficulty. In each of these instances, bodies and body parts either legally or effectively have been reduced to the status of nonproperty in the hands of the individuals from whom they come. Yet the same bodies and body parts are most certainly property — and valuable property at that — in the hands of all who follow, including medical and research institutions, private biobanks, and other businesses. In other words, in America, bodies and body parts are not property, except when they are.

Endless ink has been spilled debating whether those who provide body products for medical or research uses should be entitled to compensation, in a free market or otherwise.<sup>20</sup> In many instances, prohibitions have been deemed necessary to protect both suppliers and recipients: Suppliers, because they may be of limited economic means and may therefore be exploited to participate in efforts not otherwise consistent with their wellbeing or desires.<sup>21</sup> Recipients, because payment may “crowd[] out” otherwise altruistic donors and leave only poor suppliers who are more likely to have and to hide a negative medical history.<sup>22</sup> Indeed, in the ordinary telling, the history of America’s prohibition on property in the body (at least for the sources of those bodies and their parts) can be traced back to a single book, Professor Richard

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<sup>18</sup> For an analysis of the distinctions in legal treatment of bodies and organs, and the market consequences, see generally Harrington & Sayre, *supra* note 4. For an examination of the history and current status of the markets in breastfeeding, human milk, and infant formula, see Fentiman, *supra* note 11, at 35–75. For a discussion of current regulations governing human research subjects and an argument to extend those regulations to cover human DNA sequencing, see Amy L. McGuire & Richard A. Gibbs, *No Longer De-identified*, 312 *SCIENCE* 370 (2006).

<sup>19</sup> See sources cited *supra* note 18.

<sup>20</sup> For a recent collection of articles exploring the issue of compensation for body products, see Symposium, *Organs and Inducements*, 77 *LAW & CONTEMP. PROBS.*, no. 3, 2014, at i. See also Natalie Ram, *Assigning Rights and Protecting Interests: Constructing Ethical and Efficient Legal Rights in Human Tissue Research*, 23 *HARV. J.L. & TECH.* 119, 132–35 (2009) (discussing the ethical and legal issues raised by the commercialization of body products); Lynette Reid, Natalie Ram & R. Blake Brown, *Compensation for Gamete Donation: The Analogy with Jury Duty*, 16 *CAMBRIDGE Q. HEALTHCARE ETHICS* 35 (2007) (examining whether gamete donation can be analogized to jury duty and viewed as either a public service or public duty).

<sup>21</sup> See I. Glenn Cohen, *Regulating the Organ Market: Normative Foundations for Market Regulation*, 77 *LAW & CONTEMP. PROBS.* no. 3, 2014, at 71, 75–79 (explaining the normative argument against the sale of organs based on concerns over coercion, undue influence, and exploitation).

<sup>22</sup> *Id.* at 74–75.

Titmuss's *The Gift Relationship*, which argued that paying blood donors led to poorer quality blood.<sup>23</sup>

But in her recent book, *Banking on the Body*, Professor Kara Swanson reveals a more complicated story, one in which the body bank arose as “more than a mere metaphor” (p. 238). Swanson surveys the history of the body bank, which began with blood but went on to shape American law and nonlegal norms governing many forms of body-product exchange. In exploring this history, Swanson invites readers to consider “how to move beyond the body bank and the legal straitjacket that is its legacy to focus on the ends of body product exchange rather than the means” (p. 243).

Part I of this Review assesses the major contributions of Swanson's book, namely Swanson's account of the concept of the body “bank” from its origins in 1937 to the present day. In the course of this history, Swanson makes two more profound points. First, her historical account reveals that, for many years, paid blood sellers were not persons to fear or the desperate poor we worry about today. Second, Swanson demonstrates that compensated “donors” offered benefits to medical professionals — and body-product recipients — not available with altruistic donors. In light of this history, Swanson closes with a call to reconsider the prohibition on payments for body products, concluding that historical experience establishes that “[b]ody products are property” (p. 243).

Swanson briefly recognizes that the history of the biobank impacts the way in which interests in body parts are constructed, not only for purposes of medical treatment, but also for research (pp. 244–45). Swanson invokes the case of John Moore, in which the Supreme Court of California famously refused even to recognize a patient's property interest in the cells taken from his body and subsequently used in research without the patient's knowledge (pp. 244–45).<sup>24</sup> But Swanson says little more on the subject. This Review picks up where Swanson leaves off. Part II establishes that the use of body products in research is relevant to Swanson's tale, for the use of body products in research and in clinical care are inextricably linked and discussions in both con-

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<sup>23</sup> See RICHARD M. TITMUSS, *THE GIFT RELATIONSHIP* 150–52, 157 (1970); Claudia Niza, Burcu Tung & Theresa M. Marteau, *Incentivizing Blood Donation: Systematic Review and Meta-Analysis to Test Titmuss' Hypotheses*, 32 *HEALTH PSYCHOL.* 941, 941–42 (2013) (describing the influence of Richard Titmuss's *The Gift Relationship*); Robert Pinker, *From Gift Relationships to Quasi-markets: An Odyssey Along the Policy Paths of Altruism and Egoism*, 40 *SOC. POL'Y & ADMIN.* 10, 13 (2006); see also ALBERT R. JONSEN, *THE BIRTH OF BIOETHICS* 206 (1998) (asserting that the ideas in *The Gift Relationship*, “together with the life-saving drama of transplantation and the American predilection for voluntary assistance to others in need,” gave rise to the no-compensation model Congress adopted in the National Organ Transplant Act).

<sup>24</sup> *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 497 (Cal. 1990) (holding that Moore's complaint against his physician and other defendants did not state a cause of action for conversion).

texts about payment for body products are often animated by similar concerns.

Finally, Part III moves beyond Swanson's historical account of the clinical body bank, demonstrating that the research realm offers both productive solutions and degrading depersonalization not yet seen in the medical market in body products. The research realm may provide guidance for "how to appropriately regulate body products as a type of property currently exchanged in many ways for many purposes" (p. 243). A shift toward greater parity between body-product producers and others in the supply chain need not entail a market-free zone or a free market. Rather, policies and lived experiences in research body banking offer property or quasi-property regimes that embrace the civic property approach for which Swanson advocates. Already there are the seeds of such developments in some clinical settings as well. In addition to guidance, however, the research realm sounds a note of caution. Its practices hint at further alienation of body products from their sources, to which the clinical body bank may yet succumb in the name of progress.

Ultimately, this Review concludes that Swanson's book serves a critical function by providing a rich account of how the United States ended up with the body banking system it has, even if Swanson herself does not delve deeply into how that history informs and differs from that of biobanking for research. In tandem with the complementary experiences of research body banking, Swanson's work makes plain that treating body products as nonproperty — but only for their sources — disserves both medical and research practices by inflicting injury on the ethical and effective governance of body banks. Doubtless, Swanson's work will inspire other scholars to question whether the body banking system we have now accurately reflects our values, rather than just the circumstances of history.

### I. SITUATING THE BODY BANK

In *Banking on the Body*, Swanson offers a historical answer for why American law and nonlegal norms often prevent the sources of body products — like blood, milk, and kidneys — from gaining remuneration for parting with these valuable resources. As Swanson recognizes, others in the chain of body-product exchange are compensated for their efforts; moreover, "[r]efusing to acknowledge markets in body parts has not stopped market allocation of these medical therapeutics" (p. 4). In order to understand why body-product exchanges for money are "consider[ed] tainted and bad" (p. 4), Swanson unravels the history of the concept of the body "bank" itself.

In recounting this history, Swanson richly explores the foundation, growth, and change over time in banks of two principal kinds: blood and breast milk. Swanson closes with some discussion about two oth-



er kinds of body banks, for sperm and (very briefly) eggs, though this discussion is far less developed than Swanson's account of blood and milk banking (pp. 198–237). Swanson capably builds, and sometimes critiques, multiple themes underlying body-product exchange, some of which have already received scholarly attention elsewhere.<sup>25</sup> These themes include the ways in which banking institutions have perpetuated gendered expectations for men and women participating in body-product exchange,<sup>26</sup> as well as the troubling role played by racial discrimination, particularly in the history of blood banking (pp. 64–65).<sup>27</sup> Important though these themes are, the focus of this Review is a different, although related, theme — one indicating that paying body-product providers may yield better, not worse, resources for both banks and their providers. Accordingly, this Review sets forth only a brief overview of Swanson's narrative before focusing more closely on this point.

Identifying when the terms “bank” and “banking” came to apply to the storage and use of human body parts is, Swanson explains, the easy part (p. 5). In 1937, Dr. Bernard Fantus “borrowed the term *bank* from the world of finance to describe the organization of stored blood in his hospital, which he sought to manage like money in the bank” (p. 5). At the time, providers of blood for transfusion often were paid professionals, and their services frequently were beyond the means of Fantus's largely low-income patients (p. 8). Where a paid blood provider was too expensive, patients and their physicians frequently prevailed upon the patient's family and friends (p. 49). Even so, a donor might not be found, as when no volunteer had a matching blood type to the patient or there was insufficient time to properly type a potential blood donor (pp. 49–50).

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<sup>25</sup> See I. Glenn Cohen, *My Body, My Bank*, 93 TEX. L. REV. 953 (2015) (reviewing KARA W. SWANSON, *BANKING ON THE BODY* (2014)) (discussing themes of gender and race as well as, inter alia, Swanson's exploration of the relationship between product liability law and the development of understandings of bio-property in *Banking on the Body*).

<sup>26</sup> Swanson notes the consistent association between paid body-product exchange and men on the one hand, and uncompensated gifting and women on the other (p. 240). Swanson looks at how, from the early days of blood transfusion, physicians and institutions expressed a preference for male blood sellers (pp. 41–44), and also observes that the growth of female blood donors coincided with the move to uncompensated blood donation during World War II (pp. 74–75). Professor Glenn Cohen presses Swanson on this point, arguing that Swanson “misses an opportunity to more deeply examine the ways in which various body banks reinforce but also subvert gender narratives over time.” Cohen, *supra* note 25, at 1006.

<sup>27</sup> Swanson describes how racial discrimination became embedded in blood banking, even as the institutions establishing and operating blood banks acknowledged that there was “no valid objection on biologic or physiologic grounds to the transfusion of patients of one race with blood from donors of another” (p. 65) (quoting Mark M. Ravitch, *The Blood Bank of the Johns Hopkins Hospital*, 115 JAMA 171, 171 (1940)).

The innovation of shelf-stable stored blood, however, enabled physicians to separate the time of blood collection from the time of blood use (pp. 52–53, 55). Fantus’s bank embraced stored blood — a controversial position at the time, but an essential element of the banking model (pp. 54–56). By severing the tie between blood provider and blood user, Fantus’s bank was able to accept and make use of blood from any healthy provider, regardless of whether that provider matched any particular patient (p. 57). Each department in the hospital was responsible for “deposit[ing],” over time, the same volume of blood it “withdr[ew]” to treat its patients (p. 57).

The hospital, in turn, extended the banking metaphor to patients directly (pp. 58–59). Patients were instructed that anyone “who had received blood had been ‘lent’ the blood by the bank and ‘owed’ a return deposit to aid another patient” (p. 58). In Fantus’s bank, therefore, debts for blood could be discharged through the provision of a reciprocal volume of blood, by a patient’s family member or by the patient at a later date (p. 56).

Fantus’s bank thus did not create a commercial market in human blood. Instead, the bank described a method of accounting for blood and ensuring an adequate supply to all, overseen and administered by medical professionals for the common good (p. 57). The key to the bank was balancing withdrawals and deposits (p. 62). As Fantus told his colleagues, “[t]he term ‘blood bank’ is not a mere metaphor” (p. 57).<sup>28</sup>

The concept of the bank spread quickly, first to blood banks throughout the United States and then to body banks of other kinds, including mothers’ milk stations (pp. 162, 165–66). By 1939, medical treatises were already describing and endorsing blood banking along the lines laid out by Fantus (p. 62). By the 1940s, what were previously known as “milk stations” or “milk bureaus” similarly adopted the language of the bank (pp. 162–68). But while the institutions collecting and distributing breast milk made use of the popular terminology, they applied the metaphor of the bank only loosely (p. 166). After all, strict debits and credits were not possible in the milk bank (p. 163).

Swanson recounts that paid sellers became a feared entity as the result of the confluence of several subsequent developments in the regulation of blood banks. First, in the post–World War II era, battles raged between the Red Cross and community blood banks that took Fantus’s blood bank metaphor ever more literally (pp. 94–99). While the Red Cross advocated against charging patients for units of blood, either in money or in blood, community blood banks and affiliated or-

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<sup>28</sup> The author quotes Bernard Fantus, *The Therapy of the Cook County Hospital: Blood Preservation*, 109 JAMA 128, 128 (1937).

ganizations emphasized the need for individuals to keep their blood “accounts” balanced (p. 107). These banks took Fantus’s language at its word, arguing that blood should be treated like “silver teaspoons” for which a patient must pay (p. 113).<sup>29</sup> “Replacement donors” became the laudable figure of the day for these banks, providing blood today to secure a credit against a future blood debt (p. 109).

In addition to these interinstitutional tensions, the blood-as-teaspoons analogy spawned difficulties of its own for the medical establishment. Patients began to sue physicians and hospitals for blood transfusions gone wrong, arguing that they were victims of defective products (p. 121). The Federal Trade Commission investigated and issued a complaint against Kansas City’s nonprofit blood banks, asserting unfair trade practices (p. 132). Medical backlash against these and other forms of liability prompted blood banks and their affiliated medical professionals to quickly reassess their rhetoric (p. 121). Several states enacted “blood shield” laws, which “defin[ed] banked blood as part of the ‘service’ of providing medical care rather than a possibly ‘unreasonably dangerous’ ‘product’” (p. 121).<sup>30</sup> And blood banks began to move away from professional donors as part of an effort “to break the connections between money and blood among supplier, bank, and recipient” (pp. 121–22). When fears about hepatitis in the blood supply began to percolate in the 1950s and 1960s (pp. 124–25), the professional donor came under further attack. Media drew links from “paid blood suppliers” to donors from the “wrong side of the tracks” and from there to “poverty” and “disease” (p. 146). That image persisted, despite mixed evidence about whether paid or philanthropic blood donors were more likely to contribute hepatitis as well as blood (p. 146).

In this shifting milieu, Richard Titmuss’s *The Gift Relationship* framed the debate over America’s blood supply not as about whether patients should pay, but about whether providers should be paid (p. 122). The influence of Titmuss’s book was significant. Indeed, *The Gift Relationship* has been described as “an established classic in the literature of social policy,” giving rise “to a debate which, in its intensity, had as much to do with the drawing as with the donation of blood.”<sup>31</sup> By focusing on the blood provider and denominating our choices as between treating blood as gift or as commodity, Titmuss’s

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<sup>29</sup> The author quotes Leon E. Mermod & Hazel H. Bond, *Blood Program of Hawaii*, in PROCEEDINGS OF BLOOD BANK INSTITUTE 25, 30 (1947) (statement of an administrator of the Blood Bank of Hawaii).

<sup>30</sup> The author quotes Patricia Kussman, Annotation, *Validity, Construction, and Application of Blood Shield Statutes*, 75 A.L.R.5th 229, § 2(a) (2000); and RESTATEMENT (SECOND) OF TORTS § 402A(1) (AM. LAW INST. 1965).

<sup>31</sup> Pinker, *supra* note 23, at 13; see also sources cited *supra* note 23.

book constrained the scope of the debate that followed. And when the first kidney transplants made hard organ donation possible, the gift/commodity debate ruled the day (pp. 156–57). The result was the National Organ Transplant Act,<sup>32</sup> which prohibits the exchange of “valuable consideration” for various organs (p. 157).<sup>33</sup>

Today, the gift/commodity dichotomy is embedded in law — at least as far as the providers of raw materials are concerned (p. 241). Organs, including bone marrow, may be gifted but not sold; blood and milk may be, but typically are not, sold; gametes are frequently bought and sold in a free market (pp. 240–41). Institutions facilitating each of these exchanges call themselves banks, but Fantus’s banking metaphor hardly applies to any of them. These institutions remain free to buy and sell their stock and trade, regardless of the price paid for the raw material (p. 245).

Swanson concludes that the history of the body bank should prompt a reconsideration of the prohibition on payments for certain body products (pp. 245–51). As Swanson observes, historical experience makes plain that “[b]ody products are property. Body products are appropriately civic property. Markets in body products can be harnessed to serve communal goals. The professional donor can be a safe and respected supplier of body products” (p. 243). Fantus’s blood bank was no “mere metaphor” (p. 57),<sup>34</sup> but neither did it require resort to or reliance on pure free-market principles to allocate blood to the highest buyer or from the lowest seller.

Along the way, moreover, Swanson makes two more profound points. First, Swanson explains that paid providers of body products have not always been associated with the desperate poor for whose protection many payment restrictions exist (p. 246). Rather, for many years before the paid blood seller became someone to fear, the “professional donor” was often a “heroic and respectable figure” (p. 42). These men (and regular blood sellers typically were men) were “m[e]n of business” (p. 115), using their bodies to earn family income not just at the office but also at the hospital blood bank (pp. 43–44). Indeed, some news articles identified blood selling as a business all its own, sufficient to allow its “healthy, full-blooded” participants to earn a liv-

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<sup>32</sup> Pub. L. No. 98-507, 98 Stat. 2339 (1984) (codified as amended at 42 U.S.C. §§ 273, 274–274e (2012)).

<sup>33</sup> 42 U.S.C. § 274e(a); see also JONSEN, *supra* note 23, at 205–08 (recounting bioethical debates surrounding organ transplantation leading up to and following enactment of the National Organ Transplant Act). See generally Mary Jo Festle, *Enemies or Allies? The Organ Transplant Medical Community, the Federal Government, and the Public in the United States, 1967–2000*, 65 J. HIST. MED. & ALLIED SCI. 48, 59–62 (2010) (explaining opposition to and support for the passage of the National Organ Transplant Act).

<sup>34</sup> The author quotes Fantus, *supra* note 28.

ing wage or tuition money (p. 43).<sup>35</sup> These men were not “down-and-outers” or poor “rovers,” but “professionals” — and robust ones at that (p. 43). Thus, blood sellers of the 1920s were “admirable physical specimens,” from whom “any American would want blood” (p. 43).

Of course, not all accounts of paid blood sellers painted such a rosy picture. As Swanson explains, alongside accounts lauding the professional were others denigrating that figure (p. 47). One magazine article recounted blood sellers “liv[ing] in a squalid boardinghouse,” who were “not eager young students or budding salesmen but broken failures” (p. 47).<sup>36</sup> Swanson’s insight, however, is that the early days of blood transfusion saw multiple narratives for paid providers of body products, not all of which were negative.

Moreover, not all paid sellers of blood and milk were interested in personal gain. For instance, members of the Greenleafton Reformed Church in Preston, Minnesota, signed up in droves to sell their blood, dedicating the proceeds to rebuild their church after a fire (p. 144).

As Fantus’s banking metaphor spread, “replacement donors” joined the professionals, accruing blood credits redeemable for future blood needs (pp. 108–09, 113). Where the professional donor earned income for his family by giving blood, “the working husband and father during the Cold War could provide for his family by purchasing blood credits with his donation” (p. 114). Unlike the extraordinary men who served as professional donors, the replacement donor was every responsible family man (p. 116). By giving blood as a “replacement donor,” he was “showing the same fiscal responsibility and ability to care for his family as he showed by maintaining a savings account” (p. 116). In this sense, the individual giving blood for practical business reasons was laudable, unlike the “shiftless minority” unable to pay for blood in cash or in kind (p. 117).

Similarly, a woman who sold her milk for pay was often lauded as doing a “double charity,” both providing milk needed by others and helping to support herself and her family (p. 37).<sup>37</sup> The shift from wet nurses to bottled breast milk, in fact, accompanied a shift in the source of breast milk for infants. While wet nurses often came from “among the bottom rungs of society,” physicians recruited sellers of bottled breast milk from women of a higher socioeconomic status (p. 36). These “healthy married mothers” (p. 36),<sup>38</sup> like the men primarily involved in blood selling, were engaged in a “legitimate trade” and “prof-

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<sup>35</sup> The author quotes Louis Schwartz, *Full-Blooded Donors*, 8 *HYGEIA* 1109, 1109 (1930).

<sup>36</sup> The author cites Charles V. Nemo, *I Sell Blood*, 31 *AM. MERCURY* 194, 194–98 (1934).

<sup>37</sup> The author quotes B. Raymond Hoobler, *An Experiment in the Collection of Human Milk for Hospital and Dispensary Uses*, 31 *ARCHIVES PEDIATRICS* 171, 173 (1914).

<sup>38</sup> The author quotes Fritz B. Talbot, *An Organization for Supplying Human Milk*, 199 *NEW ENG. J. MED.* 610, 610 (1928).

itable business" in human milk, enabling their families to maintain or even rise in socioeconomic status (p. 37).<sup>39</sup>

In sum, individuals who provided blood or milk expecting something in return, whether in cash or in kind, were often admirable figures in earlier days of blood banking. In ways unfamiliar today, body banking for personal benefit was not an activity for the poor or desperate. Rather, at times it was a matter of good sense and familial responsibility.

Second, Swanson chronicles how compensated donors, whether remunerated with cash or credit, offered physicians — and body-product recipients — material benefits not available with altruistic donors. Swanson demonstrates that remunerated donors were more readily susceptible to medical oversight. In particular, physicians could demand more information, blood tests, and physical inspection. Local hospitals routinely maintained registries of paid blood sellers who were regularly available, blood typed, and screened for disease (p. 44). The Mayo Clinic's one thousand registered blood sellers each were required to undergo "a general physical examination, urinalysis, and a syphilis test every six months" (p. 44). New York City's Blood Transfusion Betterment Association maintained a registry of professional donors available to multiple city hospitals (p. 45). The Association rejected roughly one-quarter of applicants for the "job of blood seller," "often on the basis of 'unprepossessing habits' or 'unpleasant personal appearance'" (p. 46).<sup>40</sup> These blood banks, whether based at hospitals or in freestanding medically supervised institutions, "sought to standardize and control donor bodies, striving to make a safe and reliable blood supply available to [their] member medical institutions" (p. 46).

Similarly, paying new mothers for their milk enabled physicians to require women to express milk under medical supervision (pp. 36–37). Milk stations in the 1920s "enforced strict hygienic procedures and monitored the mothers" expressing milk on site (p. 33). Women washed (or were washed) under supervision, garbed themselves in gowns (often from head to toe), and submitted to physical examination before expressing milk for pay (p. 33). When the Detroit milk bureau permitted certain "reliable" women to express milk at home and send it to the hospital, it paid less for that milk than for milk provided on site and under supervision (p. 33). Payment, in other words, yielded stricter control.

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<sup>39</sup> The author quotes James A. Tobey, *A New Foster-Mother*, 7 *HYGIEIA* 1110, 1110–11 (1929).

<sup>40</sup> The author quotes E.H. Lewinski Corwin, *Blood Transfusions and Donors*, 4 *BULL. AM. HOSP. ASS'N* 116, 119 (1930). Of course, what constituted "unprepossessing habits" or "unpleasant personal appearances" were likely to be largely subjective inquiries that could provide cover for bias.

Many of the physicians involved in these efforts also sought to make the pay for milk substantial enough that a woman could “support herself and her child,” without needing to return immediately to work (p. 37).<sup>41</sup> Others required new mothers to bring their own infants to the hospital at appointed times (p. 37). Through this requirement, women also obtained new-baby medical care that otherwise would have frequently been unaffordable (p. 37). Payment thus permitted physicians not only to exercise greater control, but also to use that control to achieve better outcomes for all involved.

## II. RECOGNIZING THE RELEVANCE OF RESEARCH

In winding her tale to a close, Swanson touches briefly on how her history of the clinical body bank intertwines with that of the research biobank (pp. 244–45). Swanson explains that “[o]ne perverse result of the blood bank battles and the resulting market backlash . . . has been a line of legal reasoning that denies property interests in body products” (p. 244). In order to avoid the language — and liability — of market products, courts and legislatures have reconceived of body products as “nonproperty” (p. 244). But this “nonproperty” lens is limited, and the result has been “a loss of supplier control over disembodied body products as well as over any profits that come from their commercialization” (p. 244).

It is here that Swanson invokes, in a single paragraph, the case of John Moore (pp. 244–45). In that case, the California Supreme Court held that a patient, John Moore, could not maintain a conversion action against his physician, related researchers, and others who had taken tissue removed from Moore’s body for treatment purposes and used that tissue for independent research and commercial purposes.<sup>42</sup> The court reached that holding by concluding that Moore had no property right in his tissue once removed from his body, and thus that no property had been converted when that tissue was subsequently used in research without Moore’s knowledge or consent.<sup>43</sup> Swanson recognizes that, for both medical and research suppliers of body products, “[o]nly the supplier of the body products is left uncompensated, prevented by law from profiting from the act of creating what becomes valuable property” (p. 245). Thus, Swanson links the history of estranging blood, milk, and other donors from their body products to the similar fate of those providing tissue for research purposes (p. 245).

This acknowledgment of the research body bank, though telling, leaves much untold about the role of research body banking in the

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<sup>41</sup> The author quotes Hoobler, *supra* note 37, at 173.

<sup>42</sup> Moore v. Regents of the Univ. of Cal., 793 P.2d 479, 487–97 (Cal. 1990).

<sup>43</sup> *Id.*

banking story more broadly. As Professor Glenn Cohen observes in his own review of Swanson's book, "one of the most important modern forms of body banking is *not* for clinical use at all but for research use."<sup>44</sup> Engagement with the research body bank intersects Swanson's clinically focused project in at least three ways.

First, the research body bank is a body bank that might well be relevant to the history Swanson sets out to tell. As Cohen has observed, the contours of the biobank are in many ways more like the financial bank that first inspired Fantus than the blood bank Fantus actually created.<sup>45</sup> The initial body bank Swanson so ably describes in her book latched on to the banking metaphor to establish a method of recordkeeping and asset management (p. 57). In so doing, Fantus's bank, and others like it, borrowed from the financial realm the depositor's perspective. Just as one may not borrow without repayment or withdraw without deposit in a financial bank, so too with the blood bank (p. 58).

But banks are not merely lockboxes in which individuals deposit their savings. Banks are also independent institutions, whose principal revenue does not come from holding funds or connecting borrowers and lenders.<sup>46</sup> The fact that most banks pay interest on deposited funds, rather than charge fees for their service, belies such a model. Rather, financial banking makes its money by investing deposited funds, hopefully to greater gains than that paid out in interest in the interim.<sup>47</sup> In other words, we can view banks from the perspective of the depositor, who wants to know she can withdraw equivalent funds in the future, or from the perspective of the bank-as-institution, which wants to use its deposits to its own ends.

Research biobanks operate in a manner somewhat similar to this second view of the bank. These banks invest the human tissue or genetic information they have acquired into research and other endeavors, with the hope that such research will bear financial fruit greater than the cost of collecting and maintaining the banks' inventories. Modern revenues in blood banking suggest that the institutional perspective is at work in that field as well.<sup>48</sup>

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<sup>44</sup> Cohen, *supra* note 25, at 988. Cohen does not engage in a substantive discussion of the research body bank, but does identify the lack of such discussion in Swanson's book. *Id.* at 988–90.

<sup>45</sup> *Id.* at 989.

<sup>46</sup> *Id.*

<sup>47</sup> *Id.*

<sup>48</sup> See, e.g., Byron Harris, *Blood Business Pits Charities Against One Another*, WFAA (Feb. 18, 2015, 10:23 PM), <http://www.wfaa.com/story/news/local/investigates/2015/02/18/carter-blood-care--american-red-cross-general-blood-blood-donations/23635415> [http://perma.cc/5P83-4ALE]; Dan Tracy, *Salaries Rise at Merged Blood Bank, Even as Revenues Fall*, ORLANDO SENTINEL (Oct. 20, 2012, 7:34 PM), [http://articles.orlandosentinel.com/2012-10-20/business/os-one-blood-florida-day1-20121020\\_1-anne-chinoda-blood-bank-oneblood](http://articles.orlandosentinel.com/2012-10-20/business/os-one-blood-florida-day1-20121020_1-anne-chinoda-blood-bank-oneblood) [http://perma.cc/M5J2-BFCV].



To be sure, the analogy between the financial bank and the research body bank is imperfect, just as it is for the clinical body bank Swanson discusses. The research body bank hews most closely to the institutional perspective of banking, and shares less with the depositor approach. That is necessarily so, as the sources of research tissue typically do not retain the right to reclaim their tissue from the bank.<sup>49</sup> Indeed, in many instances individuals are legally barred from obtaining the return of their excised biological materials, as federal and many state laws have classified such materials as hazardous waste.<sup>50</sup> The depositor perspective is not entirely absent from the research body bank, however. In one prominent case, the Eighth Circuit held that tissue providers retained the right to request destruction of their cells so that they would no longer be research subjects against their will.<sup>51</sup> Similarly, 23andMe permits its customers who consent to research participation to opt out later.<sup>52</sup>

By leaving research biobanks out of her history, Swanson has given us an incomplete account of the body bank. Moreover, by hewing to the depositor perspective, Swanson overlooks the institutional perspective of banking that could bring additional richness to her analysis of property in the body.

Second, Swanson's history of the clinical body bank is also relevant to matters of research governance. These two fields are inextricably linked. To state the obvious, clinical treatment often results from medical research,<sup>53</sup> and medical research is designed to develop new clinical

<sup>49</sup> See *Wash. Univ. v. Catalona*, 490 F.3d 667, 676 (8th Cir. 2007) (“Noticeably absent from the record is any mention the [research participants] ever were informed they could physically withdraw or request the return of their biological samples.”).

<sup>50</sup> See, e.g., 29 C.F.R. § 1910.1030(b) (2013) (defining “Regulated Waste” as including “[a]ny unfixed tissue or organ (other than intact skin) from a human (living or dead)”); CAL. HEALTH & SAFETY CODE § 7054.4 (West 2015) (“Notwithstanding any other provision of law, recognizable anatomical parts, human tissues, anatomical human remains, or infectious waste following conclusion of scientific use shall be disposed of by interment, incineration, or any other method determined by the state department [of health services] to protect the public health and safety.”); *Catalona*, 490 F.3d at 676 (“[I]n no event *could* the samples physically be returned to their donors. Federal and state regulations prohibit such a result by defining excised body tissue and blood as hazardous substances or infectious waste, and by articulating the proper disposal method.”); *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 491–92 (Cal. 1990) (discussing how Moore’s claim of a continuing property interest in his excised cells was undermined by California health and safety codes regulating the disposal of human tissue).

<sup>51</sup> *Catalona*, 490 F.3d at 675 (“[T]he [research participant] is entitled to request his biological materials no longer be used, and under the terms of the brochures (and some of the consent forms as well), the materials would be identified and destroyed upon request.”).

<sup>52</sup> 23ANDME, *supra* note 15 (“Research participation is an opt-in choice during the kit registration process . . . . You can opt-out of research at any time.”).

<sup>53</sup> For instance, Jonas Salk first developed the polio vaccine to aid in the clinical prevention of polio; the effectiveness of that vaccine was validated through laboratory testing using HeLa cells. See REBECCA SKLOOT, *THE IMMORTAL LIFE OF HENRIETTA LACKS* 93–97 (2010). The HeLa cells, in turn, derived from a sliver of cancerous cervical tissue taken from Henrietta Lacks,

cal treatments.<sup>54</sup> Indeed, the line between clinical treatment and medical research is sometimes murky.<sup>55</sup> Though not part of controlled research studies, early efforts to transfuse blood, for instance, were “risky and experimental” (p. 16). Recent efforts to increase the availability of experimental drugs and treatments to terminally ill patients similarly straddle the line between research and treatment.<sup>56</sup>

The research/treatment relationship also lies at the heart of biobanking. As set forth above, biobanks are valuable because of the information they hold and the research they can support.<sup>57</sup> Cells taken from Henrietta Lacks in 1951 during the course of medical treatment (without consent, much less payment, for their use in research) were valuable because they gave rise to the first immortal cell line, a new material for research purposes.<sup>58</sup> The uses to which those cells were put, moreover, multiplied their value exponentially. HeLa cells (from *Henrietta Lacks*) “contributed to the development of a polio vaccine, the discovery of human telomerase and countless other advances.”<sup>59</sup> Modern biobanks pursue the same research/treatment hybrid.<sup>60</sup> Lawsuits waged over ownership of biobank materials make plain not only their value, but also the overlapping relationship between research and treatment. For instance, in one case, a university and a former faculty

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when she was a patient at The Johns Hopkins Hospital. *Id.* at 33, 40–41. Numerous other medical advances have also developed from research involving human biological tissue. *See, e.g., id.* at 316.

<sup>54</sup> The relationship between medical research and clinical treatment is not always positive. Advances in medical research may also hinder clinical treatment. For instance, prior to the Supreme Court’s decision in *Association for Molecular Pathology v. Myriad Genetics, Inc.*, 133 S. Ct. 2107 (2013), one survey reported that a quarter of responding laboratories had stopped offering or developing a genetic test in response to patent enforcement efforts. Mildred K. Cho et al., Special Article, *Effects of Patents and Licenses on the Provision of Clinical Genetic Testing Services*, 5 J. MOLECULAR DIAGNOSTICS 3, 7 (2003). Fifty-three percent of responding laboratories reported that they had “decided not to develop or perform a test/service for clinical or research purposes because of a patent.” *Id.* at 5. The Supreme Court’s decision in *Association for Molecular Pathology* held that naturally occurring genetic sequences may not be patented. 133 S. Ct. at 2111.

<sup>55</sup> *Cf., e.g.,* Editorial, *How Can We Draw the Line Between Clinical Care and Medical Research?*, 4 PLOS MED. 1707 (2007) (discussing ethical issues raised by the difficulty in distinguishing between clinical care and medical research).

<sup>56</sup> *See* Rebecca Dresser, *The “Right to Try” Investigational Drugs: Science and Stories in the Access Debate*, 93 TEX. L. REV. 1631, 1632 & n.3 (2015) (discussing these efforts and observing that at least twelve states have enacted right-to-try laws, which allow terminally ill patients to gain access to drugs not yet FDA approved).

<sup>57</sup> *See* SKLOOT, *supra* note 53; sources cited *supra* note 12.

<sup>58</sup> *See generally* SKLOOT, *supra* note 53 (discussing Lacks’s life and illness, and scientists’ subsequent use of her cells).

<sup>59</sup> Ewen Callaway, *Deal Done over HeLa Cell Line: Family of Henrietta Lacks Agrees to Release of Genomic Data*, 500 NATURE 132, 132 (2013).

<sup>60</sup> Henderson et al., *supra* note 1, at 5, 7 (reporting that more than half of American research biobanks include specimens obtained from clinical care, and that more than half also were “established primarily to facilitate research on a particular disease or type of disease,” *id.* at 7).

member fought over ownership of a biobank containing tissue samples from men who had had their prostates removed as part of their medical treatment.<sup>61</sup> These men were patients first, became research subjects, and hoped to benefit from the fruits of that research in the end.<sup>62</sup>

But the relationship between research and treatment goes deeper. Institutions engaged in research have sometimes justified their non-payment for body products by citing their research goals, while simultaneously charging high rates to others to use the treatments arising from that research. For instance, Prolacta explains on its website that it has “invested over 40 million dollars in research, clinical studies and facilities to develop and test our human milk derived products. This world class research and development would not have been possible in a non-profit business model.”<sup>63</sup> This explanation makes little sense, as world-class research is routinely conducted at nonprofit universities. Nonetheless, Prolacta’s research-based justification for its for-profit status, coupled with its encouragement to women to provide raw human breast milk for little or no compensation, exposes an awkward disjunction between (lack of) profit for sources of biological materials and tissue sources and profit for others in the distribution chain similar to that seen in clinical body banking more broadly (p. 245).

Third, as with the clinical body bank, concerns about exploitation of those with little information, education, or other options for obtaining income animate modern discussions about remuneration for providers of research tissue.<sup>64</sup> The literature on the buying and selling of body products (“taboo trades”) is extensive, and this Review can give only a brief overview.<sup>65</sup> Concerns about exploitation are one of several principal objections to body-product exchanges involving money.<sup>66</sup> Exploitation is of concern when a transaction is harmful to one or both parties. That is, we will say that an individual has been wrongly ex-

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<sup>61</sup> *Wash. Univ. v. Catalona*, 490 F.3d 667 (8th Cir. 2007) (recognizing Washington University as the owner of tissue and other samples provided to it under research programs overseen by a urology specialist, Dr. Catalona); *see also* *Greenberg v. Miami Children’s Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1074, 1076 (S.D. Fla. 2003) (dismissing the conversion claim and finding that individuals providing tissue and blood samples for research on Canavan disease made “donations to research without any contemporaneous expectations of return of the body tissue and genetic samples,” *id.* at 1074).

<sup>62</sup> *See* Brief of Appellant-Defendants Richard Ward, et al. at 40, *Catalona*, 490 F.3d 667 (Nos. 06-2286 & 06-2301) (“[T]issue samples provide a record of the state of patients’ cancer at the time of their surgery. Comparison of such samples to later tissue biopsies can provide important information about the progress of the disease and response to treatment.”).

<sup>63</sup> PROLACTA BIOSCIENCE, *supra* note 7 (responding to the question: “Is Prolacta a for-profit company?”).

<sup>64</sup> *See, e.g.*, Donna Dickenson, Commentary, *Commodification of Human Tissue: Implications for Feminist and Development Ethics*, 2 DEVELOPING WORLD BIOETHICS 55 (2002).

<sup>65</sup> For a more extensive overview, *see* Cohen, *supra* note 21, at 73–80.

<sup>66</sup> *See id.* at 75–79.

ploited if the buyer benefits from the transaction, the seller is harmed, and the seller only agreed to the transaction due to some characteristic of the seller, such as her poverty or age.<sup>67</sup> Absent that characteristic, the seller “would not ordinarily be willing to agree.”<sup>68</sup> As Swanson observes, payment for blood suppliers receded as the public came to associate paid suppliers with “poverty” and the “wrong side of the tracks” (p. 146) — socioeconomic conditions that may make an individual more susceptible to harmful exploitation. Concerns about exploitation may be of increasing importance in the clinical domain, given the growth of “transplant tourism.”<sup>69</sup>

Similar concerns about exploitation populate policy and discussion about payments for research participation. Nearly all ethics and research organizations interacting with research biobanks have “adopt[ed] some version of a noncommercialization position,” with some identifying the removal of human tissue specifically for profit as immoral.<sup>70</sup> These commitments against payment for tissue may have concrete policy applications. Thus, when in 2009 New York announced that it would permit state-funded researchers to pay women to provide eggs for stem cell research, “critics worr[ie]d that the move could lead to the exploitation of women, especially poor women, who tend not to be in demand for infertility donation.”<sup>71</sup> As with paid blood sellers in the 1960s, paid egg providers are frequently the subject of controversy and criticism.<sup>72</sup> Where eggs are to be used for clinical reproductive purposes, professional organizations like the American Society for Reproductive Medicine (ASRM) and the Society for Assisted Reproductive Technology (SART) have established guidelines regarding the amount that egg providers may be paid, responding to fears of exploitation.<sup>73</sup> Relatedly, where eggs are to be used for re-

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<sup>67</sup> *Id.* at 78.

<sup>68</sup> *Id.*

<sup>69</sup> See I. Glenn Cohen, *Transplant Tourism: The Ethics and Regulation of International Markets for Organs*, 41 J.L. MED. & ETHICS 269, 282 (2013) (defining “transplant tourism” as “travel abroad to purchase organs for transplant,” *id.* at 269, and observing that transplant tourism is an “increasingly common response to worldwide shortages of organs,” *id.* at 282).

<sup>70</sup> ROBERT F. WEIR & ROBERT S. OLICK, WITH JEFFREY C. MURRAY, *THE STORED TISSUE ISSUE* 123 (2004); see also B.M. Knoppers & C.M. Laberge, *Research and Stored Tissues: Persons as Sources, Samples as Persons?*, 274 JAMA 1806, 1806 (1995) (“[I]nternationally individual agreements to share in profits with the [tissue providers] are often considered morally repugnant.”).

<sup>71</sup> Rob Stein, *N.Y. to Pay for Eggs for Stem Cell Research*, WASH. POST (June 26, 2009), [http://www.washingtonpost.com/wp-dyn/content/article/2009/06/25/AR2009062501931\\_pf.html](http://www.washingtonpost.com/wp-dyn/content/article/2009/06/25/AR2009062501931_pf.html) [<http://perma.cc/DF64-T98P>].

<sup>72</sup> See, e.g., David Tuller, *Payment Offers to Egg Donors Prompt Scrutiny*, N.Y. TIMES (May 10, 2010), <http://www.nytimes.com/2010/05/11/health/11eggs.html>.

<sup>73</sup> See Ethics Comm. of the Am. Soc’y for Reprod. Med., *Financial Compensation of Oocyte Donors*, 88 FERTILITY & STERILITY 305 (2007). SART is an affiliated society of ASRM and has adopted the ASRM statement on financial compensation for egg donors as its own. See *Ethics Committee Documents*, SOC’Y ASSISTED REPROD. TECH., <http://www.sart.org/EthicsReports>

search, concerns about exploitation feature prominently. In both instances, policymakers and the public have expressed uneasiness at the buying and selling of human eggs and about the choices that women may make when substantial sums of money are on the table.

Moreover, here too international practices may heighten concerns about exploitation. Research may be conducted in one part of the world, where labor and resources are relatively inexpensive, while the products produced from that research serve the needs and interests of those in wealthier countries.<sup>74</sup> In this way, as with transplant tourism, the burdens on those producing tissue for research may fall on distinctly different populations than those who reap the benefits of that research.<sup>75</sup>

Given the scope of Swanson's historical project, it is understandable that Swanson does not explore these links between the clinical and research domains. Nonetheless, her book provides a basis for delving into these matters more deeply.

For one thing, Swanson's historical account of the clinical body bank gives new reason to question whether exploitation of society's most vulnerable is a necessary outcome when payment, in cash or other forms, is provided.<sup>76</sup> The history of the "professional" and "replacement" donor indicates that remuneration, in cash or in kind, can give rise to a healthier and more predictable population of body-product suppliers than can a reliance on unremunerated donations alone. Moreover, that history suggests that a remunerated population may well be equally as financially established as an unremunerated population of donors. The same may well be true for supplying the research body bank. In the context of disease-specific research, for instance, providing remuneration in some form may yield broader participation from discrete disease-afflicted populations — or encourage such populations to grant researchers access to basic research material.<sup>77</sup>

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[<http://perma.cc/HF64-7PVV>] (linking to ASRM's statement among SART's Ethics Committee documents). Some oocyte donors have challenged these guidelines in a class action antitrust suit. See *Class Action Complaint, Kamakahi v. Am. Soc'y for Reprod. Med.*, No. 4:11-CV-01781 (N.D. Cal. Apr. 12, 2011); Ashby Jones, *Putting a Price on a Human Egg*, WALL ST. J. (July 26, 2015, 7:14 PM), <http://www.wsj.com/articles/putting-a-price-on-a-human-egg-1437952456>.

<sup>74</sup> See Dickenson, *supra* note 64, at 57–63 (arguing that the human eggs required for therapeutic cloning research are likely to come from women in the Southern Hemisphere and support research in the Northern Hemisphere, with the fruits of that research similarly available only to those in the North); see also *Implementation of Proposition 71, the Stem Cell Research and Cures Act: Hearing Before the S. Comm. on Health, S. Subcomm. on Stem Cell Research Oversight, and the Assemb. Comm. on Health*, 2005–06 Sess. (Cal. 2005) (statement of Francine Coeytaux, Pro-Choice Alliance for Responsible Research), [http://shea.senate.ca.gov/sites/shea.senate.ca.gov/files/PROP\\_71\\_OVERSIGHT\\_COEYTAUX.doc](http://shea.senate.ca.gov/sites/shea.senate.ca.gov/files/PROP_71_OVERSIGHT_COEYTAUX.doc) [<http://perma.cc/TZ8E-D6QQ>] (noting that so long as financial inducement is available, most human eggs obtained for therapeutic cloning research will come from poor women).

<sup>75</sup> See Ram, *supra* note 20, at 133.

<sup>76</sup> See *supra* pp. 501–02.

<sup>77</sup> See *infra* notes 85–91 and accompanying text.

Moreover, just as paying suppliers of blood and milk banks enabled physicians to exercise greater medical oversight of those suppliers, payment may yield similarly increased medical oversight where the research body bank is at issue. Consider the use of human eggs for research. As set forth above, concerns about paying women for their eggs often include concerns about exploitation.<sup>78</sup> Yet payment may in fact have the opposite result. With payment, those responsible for screening potential egg providers may have a unique opportunity to ensure the wellbeing of the women in their care.<sup>79</sup> For instance, a broader potential donor pool might permit screening to ensure that egg providers are healthy enough to undergo egg retrieval, understand the procedures at issue, and share the goals of the research to be completed.<sup>80</sup> While nonpayment is one means of shaping the pool of potential egg providers, donor screening and oversight is another — and one perhaps more finely tuned to the needs of both researchers and egg providers.<sup>81</sup> Thus, as in the clinical context, payment might well permit researchers, and the physicians often responsible for collecting research tissue in the first instance, to use that payment to achieve better outcomes for all.

### III. CLINICAL LESSONS FROM THE RESEARCH BODY BANK

Just as Swanson's account of clinical body banking for blood and milk can help inform our research governance, our experiences with biobanking for research purposes offer insight into future paths that clinical body banking might take. Here, biobanking practices offer cause for both hope and alarm.

Biobanking gives reason to hope for the future of clinical body banking by providing concrete examples of how the contributions of

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<sup>78</sup> See *supra* notes 71–75 and accompanying text.

<sup>79</sup> Swanson discusses how physicians involved in milk banking sometimes provided new baby care along with collecting milk from donor mothers, and set payments for milk donations at levels substantial enough to permit a new mother to “support herself and her child,” rather than merely at the lowest price a market might bear (pp. 36–37) (quoting Hoobler, *supra* note 37, at 173).

<sup>80</sup> Swanson's work discusses the increased oversight — and rejection rate — that some blood banks were able to exercise in working with professional donors (p. 46).

<sup>81</sup> Relying on nonpayment to shape the population of women willing and qualified to provide eggs for research may indicate, in addition to a concern about exploitation, a lack of trust that the researchers and physicians involved in such research will not engage in harmful exploitation. Such concerns are not without foundation. Indeed, some researchers, and physicians involved in research, have acted in seriously unethical ways. See, e.g., JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (1993); Vicki S. Freimuth et al., *African Americans' Views on Research and the Tuskegee Syphilis Study*, 52 *SOC. SCI. & MED.* 797, 799 (2001) (“Abuse of human subjects involved in research has been well documented, and modern examples include the Human Radiation Experiments conducted by the US Government, birth control studies on women of color, the Brooklyn Jewish Chronic Disease Hospital and the Willowbrook Hospital cases, among others . . .”).

individuals providing the raw materials for research may be recognized without adopting a pure market for such materials. The research realm has, on occasion, embraced relationships with tissue providers that are neither noncompensatory nor purely market based in nature. Indeed, at least one prominent international bioethics organization has sanctioned benefit sharing as an ethical part of human tissue research. The Human Genome Organization (HUGO) is an international organization of scientists involved in human genetics that seeks to facilitate effective, efficient, and ethical research on the human and other genomes.<sup>82</sup> Like other bodies' ethical guidelines for research involving humans, HUGO's *Statement on the Principled Conduct of Genetics Research* recommends prohibiting "undue inducement through compensation for individual participants, families, and populations."<sup>83</sup> Yet the *Statement* clarifies that this recommendation does not encompass "agreements with individuals, families, groups, communities or populations that [foresee] technology transfer, local training, joint ventures, provision of health care or on information infrastructures, reimbursement of costs, or the possible use of a percentage of any royalties for humanitarian purposes."<sup>84</sup> HUGO thus distinguishes between direct compensation and benefit sharing, though both are forms of remuneration.

HUGO's recognition that remuneration may play a role in ethical and effective research practices opens the door to imagining various forms of alternative compensation, some of which have already gained a foothold in modern research practice. For instance, PXE International, a patient advocacy group for individuals suffering from pseudo-xanthoma elasticum (PXE), a rare genetic disease, successfully negotiated for co-ownership of any patents that resulted from study of blood samples collected from PXE patients and their families.<sup>85</sup> PXE International was able to secure this arrangement by assembling its own biobank and withholding access to its resources until researchers

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<sup>82</sup> See Human Genome Org., Ethical, Legal, and Soc. Issues Comm., *Statement on the Principled Conduct of Genetic Research*, 6 EUBIOS J. ASIAN & INT'L BIOETHICS 59, 59-60 (1996), <http://www.eubios.info/HUGO.htm> [<http://perma.cc/ME58-HBC4>].

<sup>83</sup> *Id.* (emphasis omitted).

<sup>84</sup> *Id.* But see Ellen Wright Clayton et al., *Informed Consent for Genetic Research on Stored Tissue Samples*, 274 JAMA 1786, 1789 (1995) (noting that some commentators "have expressed concern that offering [tissue providers] a share of profits would be manipulative because the possibility that a profitable product will be developed from any particular research project is so low").

<sup>85</sup> See Ram, *supra* note 20, at 162; see also Donna M. Gitter, *Ownership of Human Tissue: A Proposal for Federal Recognition of Human Research Participants' Property Rights in Their Biological Material*, 61 WASH. & LEE L. REV. 257, 262-63 (2004); Paul Smaglik, *Tissue Donors Use Their Influence in Deal over Gene Patent Terms*, 407 NATURE 821, 821 (2000).

agreed that any resulting intellectual property rights would be shared.<sup>86</sup>

This approach, a form of benefit sharing, afforded tissue providers at least two forms of important remuneration. First, because PXE International controlled access to its repository of human tissue, it gave PXE International members, who were the sources of that tissue, a seat at the table in determining which research projects would be conducted with their cells.<sup>87</sup> Securing a greater level of control over the research conducted with their tissue may well have borne both dignitary and utilitarian fruit for research participants and researchers alike.<sup>88</sup> Second, by conditioning access to the repository on contractual agreements to share inventorship rights in any resulting patents, PXE International secured a share of the rewards — financial, clinical, and otherwise — resulting from completed research.<sup>89</sup> In so doing, PXE International intentionally adopted the civic property model that Swanson advocates in her book. PXE International “embraced the notion of commodification, but only if it could be consciously subordinated to the needs and control of” the community of PXE patients and their families.<sup>90</sup> The model established by PXE International has

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<sup>86</sup> Ram, *supra* note 20, at 162; see also Jon F. Merz et al., *Protecting Subjects’ Interests in Genetics Research*, 70 AM. J. HUM. GENETICS 965, 966 (2002).

<sup>87</sup> See Donna Dickenson, *Alternatives to a Corporate Commons: Biobanking, Genetics and Property in the Body*, in PERSONS, PARTS AND PROPERTY 177, 191–92 (Imogen Goold et al. eds., 2014). A seat at the table is not an ordinary occurrence. Indeed, the National Institutes of Health made headlines when it gave a literal seat at the table to the descendants of Henrietta Lacks in determining which research projects using the HeLa genome should be funded. See Callaway, *supra* note 59, at 132.

<sup>88</sup> See Ram, *supra* note 20, at 127 (“[R]espect for the tissue provider’s interest in control emerges not only from considerations of respect for human dignity, but also from more consequentialist considerations about maximizing the amount of tissue available for research.”).

<sup>89</sup> *Id.* at 162; Merz, *supra* note 86, at 966. The contrast between the experience of PXE International and of participants in a biobank targeting Canavan disease could not be more striking. In the latter case, families of sufferers of Canavan disease gave a research team access to a biobank of their tissue samples. See *Greenberg v. Miami Children’s Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1067 (S.D. Fla. 2003). The lead researcher subsequently obtained a comprehensive patent on the gene responsible for the disease. *Id.* The families — who had provided the valuable tissue that made discovery of that gene (and gene variant) possible — lost a claim for conversion against the researcher and his employer. *Id.* at 1076. A settlement ultimately exempted researchers and some laboratories from paying a royalty fee to use the patented gene. Dickenson, *supra* note 87, at 193. Absent that settlement, however, a failure to negotiate contractual terms explicitly and in advance would have left the providers of that valuable tissue without the right to access the genetic information pertaining to Canavan disease.

<sup>90</sup> Dickenson, *supra* note 87, at 191. Swanson discusses the civic property model in the context of clinical body banking, but research body banking may, indeed, be a better fit. The fruits of the research body bank may yield benefits — research discoveries and developments — that redound to whole communities and populations. By contrast, the stores of the clinical body bank typically benefit individuals one at a time: each blood bag comes from one individual and treats one individual. While the civic property model Swanson advocates still carries weight in suggesting how



since spread, and so has its civic property approach: “PXE International has become a well-known model for the way it has leveraged its control of the biobank *qua* biocapital in order to achieve collective goals.”<sup>91</sup>

Benefit sharing might offer a way to resolve the property dilemma at the heart of the body bank. Benefit sharing compensates tissue providers for their contributions, while minimizing the economic, and potentially exploitative, incentive to provide tissue. There is good reason to believe such a model could be successful in banking body products other than for research purposes. The seeds of a benefit-sharing approach are visible in the history of body banking Swanson recounts. When members of the Greenleafton Reformed Church dedicated the proceeds of their blood sales to rebuild their church after a fire, they were seeking a form of remuneration other than cold, hard cash in their own hands (p. 144). Although church members received individual cash payments in exchange for their blood, those payments were dedicated to a community purpose — to the tune of \$27,000 over eight years (p. 144). In the 1950s, the Mayo Clinic categorized “church donors” (those designating their cash payments for such projects) separately from other “professional” and “replacement” donors (p. 144). Indeed, the Clinic “reported a waiting list of groups hoping to join the ranks of church donors” (p. 144). As with PXE International, the civic property model Swanson advocates is also evident here.

The spectrum of possible remuneration schemes is broader still. Replacement donors earning blood credits redeemable for future health care needs, for instance, sought and received individual or familial benefits (p. 109). As Swanson explains, the replacement donor embodied “the same fiscal responsibility and ability to care for his family as he showed by maintaining a savings account” (p. 116). But the benefits to replacement donors came in a nontraditional form of compensation: standardized blood credits instead of cash. These exchanges thus offered remuneration to their participants that cannot easily be categorized as relying on either market or gift exchange.

Modern kidney exchanges similarly defy categorization.<sup>92</sup> As described above, current federal law prohibits the transfer of a kidney

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the stores of the clinical body bank might be collected and dispersed, that model nonetheless operates somewhat differently in the research context.

<sup>91</sup> David E. Winickoff, *Partnership in U.K. Biobank: A Third Way for Genomic Property?*, 35 J.L. MED. & ETHICS 440, 450 (2007); see also Dickenson, *supra* note 87, at 192–93 (discussing subsequent biobanking efforts, including the Genetic Alliance, Science Commons, and Cancer Commons).

<sup>92</sup> See Kieran Healy & Kimberly D. Krawiec, Essay, *Custom, Contract, and Kidney Exchange*, 62 DUKE L.J. 645, 650 (2012) (“Although NEAD-chain professionals leverage the available social imaginaries of gift exchange and contract at different points of the transplant process, neither perfectly meets the practical demands of the NEAD system.”).

for “valuable consideration.”<sup>93</sup> Yet federal law also treats “human organ paired donation” as an exception to the prohibition on “valuable consideration.”<sup>94</sup> From this exception, kidney exchanges and longer “non-simultaneous, extended, altruistic-donor (NEAD) chains” have emerged.<sup>95</sup> A paired kidney exchange “involves two patient-donor couples, for each of whom a transplant from donor to intended recipient is infeasible, but such that the patient in each couple could feasibly receive a transplant from the donor in the other couple. This pair of couples can then exchange donated kidneys.”<sup>96</sup> A NEAD chain is a more elaborate form of paired exchange, in which a single altruistic donor initiates “a chain of transplants among a series of donor-patient pairs. Each donor has a kidney that is incompatible with ‘her’ patient, so instead each donates her kidney to the compatible patient of another donor-patient pair, forming the next link in the chain.”<sup>97</sup> Like replacement donors, kidney donors in such exchanges reap individualized but in-kind compensation — kidneys for their previously unmatched relatives or friends. This is remuneration, though it is treated as altruistic under current American law.

Building on the experience with kidney exchanges, scholars have also discussed benefit-sharing and directed-donation schemes. Professors Stephen Choi, Mitu Gulati, and Eric Posner have proposed “altruism exchanges” as a solution to the persistent shortage of available kidneys for transplantation.<sup>98</sup> Such exchanges would function as an intermediary enabling “people to donate kidneys (and other things) in return for a commitment by others to make charitable donations or engage in charitable acts.”<sup>99</sup> Such exchanges would rely on the same principle that animates the exception in federal law permitting kidney exchanges.<sup>100</sup> Choi and colleagues argue that permitting kidney donors to extract monetary or other donations to causes of their choice, rather than either cash for themselves or reciprocal kidney donations, would be consistent with the focus on altruistic, non-self-directed donation currently prized (and permitted) under U.S. law.<sup>101</sup>

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<sup>93</sup> 42 U.S.C. § 274e(a) (2012).

<sup>94</sup> *Id.*

<sup>95</sup> Stephen J. Choi, Mitu Gulati & Eric A. Posner, *Altruism Exchanges and the Kidney Shortage*, 77 LAW & CONTEMP. PROBS., no. 3, 2014, at 289, 296.

<sup>96</sup> Alvin E. Roth et al., *Kidney Exchange*, 119 Q.J. ECON. 457, 459 (2004).

<sup>97</sup> Healy & Krawiec, *supra* note 92, at 647; see also Kevin Sack, *60 Lives, 30 Kidneys, All Linked*, N.Y. TIMES (Feb. 18, 2012), <http://www.nytimes.com/2012/02/19/health/lives-forever-linked-through-kidney-transplant-chain-124.html> (discussing “the longest chain of kidney transplants ever constructed,” involving sixty people: thirty donors and thirty recipients).

<sup>98</sup> Choi, Gulati & Posner, *supra* note 95, at 292.

<sup>99</sup> *Id.*

<sup>100</sup> *Id.* at 295 (explaining Congress’s intent behind the exception to the “valuable consideration” prohibition).

<sup>101</sup> *Id.* at 300.

The benefit-sharing principle articulated by HUGO and pursued by PXE International in the context of the research body bank suggests that remuneration may be an appropriate part of biobank governance. The history of the clinical body bank and growing number of modern examples indicate that the same kind of principle may prove successful in the clinical context. Together, these examples offer an array of arrangements, neither purely gift nor market based, for recognizing that the body products currently housed and used in body banking are property not merely for those who operate the body bank, but also for those who supply it.

On the flipside of benefit sharing, practices in research biobanking also suggest an approach to body banking that exacerbates the depersonalization of body products already embedded in some forms of body-product regulation. Today, hundreds of millions of specimens of human biological material are stored in hundreds of biobanks throughout the United States, and the number of specimens continues to grow by the tens of millions each year.<sup>102</sup> In many instances, research specimens have been collected for “one purpose [like medical treatment] and subsequently used for another.”<sup>103</sup> According to one recent study, more than half of American research biobanks reported that they included in their collections “[r]esidual specimens acquired from clinical care in hospitals, clinical laboratories, or pathology departments.”<sup>104</sup> Such secondary use of tissue often occurs without consent from the tissue source, “either because the [Institutional Review Board] waives that requirement or because identifiers are removed so that the samples are no longer deemed to involve ‘human subjects.’”<sup>105</sup> Current American standards for legal and ethical research require informed consent only from persons whose “[i]dentifiable private infor-

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<sup>102</sup> Mark A. Rothstein, *Protecting Privacy in Genetic Research on Alcohol Dependence and Other Addictions*, in *GENETIC RESEARCH ON ADDICTION* 84, 84 (Audrey R. Chapman ed., 2012); see also 1 NAT'L BIOETHICS ADVISORY COMM'N, *RESEARCH INVOLVING HUMAN BIOLOGICAL MATERIALS: ETHICAL ISSUES AND POLICY GUIDANCE* 13 (1999) (“[A]s of 1998, [it is estimated that] more than 282 million specimens of human biological materials were stored in the United States, accumulating at a rate of more than 20 million cases per year . . .”).

<sup>103</sup> Ellen Wright Clayton, *Incidental Findings in Genetics Research Using Archived DNA*, 36 *J.L. MED. & ETHICS* 286, 287 (2008); see also *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 486–82 (Cal. 1990) (discussing the removal of patient's spleen to combat hairy-cell leukemia and the subsequent use of spleen cells for commercial production of a cell line to produce lymphokines); Amy L. McGuire, Timothy Caulfield & Mildred K. Cho, *Research Ethics and the Challenge of Whole-Genome Sequencing*, 9 *NATURE REVIEWS GENETICS* 152, 155 (2008) (discussing ethical difficulties and recommendations regarding secondary use of human tissue in the context of whole-genome research).

<sup>104</sup> Henderson et al., *supra* note 1, at 7.

<sup>105</sup> Clayton, *supra* note 103, at 287 (quoting OFFICE FOR HUMAN RESEARCH PROTS., U.S. DEP'T OF HEALTH & HUMAN SERVS., *GUIDANCE ON RESEARCH INVOLVING CODED PRIVATE INFORMATION OR BIOLOGICAL SPECIMENS* (2004)).

mation” is at issue.<sup>106</sup> Researchers routinely avoid these stringent requirements by de-identifying or anonymizing the human biological samples with which they work.<sup>107</sup>

The use of human tissue for research without consent is not idle speculation. The case of John Moore, whom Swanson names in her book to briefly link clinical and research body banking, involved the unconsented-to use of Moore’s spleen cells in research after Moore’s

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<sup>106</sup> 45 C.F.R. § 46.102(f) (2014) (defining “human subject” for purposes of the Common Rule, which governs research involving human subjects conducted using federal monies, to include “a living individual about whom an investigator (whether professional or student) conducting research obtains . . . [i]dentifiable private information”). The Common Rule requires federally funded researchers to provide human subjects with extensive information in the course of obtaining informed consent, including information about the expected risks and benefits of the research and confidentiality procedures to be followed. *Id.* § 46.116(a)(2)–(3), (5). The regulations also specify that protected “private information” is information that is “individually identifiable (i.e., the identity of the subject is or may readily be ascertained by the investigator or associated with the information).” *Id.* § 46.102(f). The FDA imposes similar requirements on all studies submitted for its review. *See* 21 C.F.R. §§ 50, 56, 812 (2015).

The agencies adhering to the Common Rule, including the Department of Health and Human Services, have recently proposed amending the definition of “human subject” to include “a living individual about whom an investigator (whether professional or student) conducting research . . . [o]btains, uses, studies, or analyzes biospecimens.” Federal Policy for the Protection of Human Subjects, 80 Fed. Reg. 53,933, 54,047 (proposed Sept. 8, 2015) (to be codified in scattered sections of the Code of Federal Regulations) (setting out proposed section \_\_\_\_, 102(e)). This definition would bring biospecimens under the scope of the Rule, regardless of whether those specimens have been anonymized or de-identified. *Id.* at 53,936 (“[I]nformed consent would generally be required for secondary research with a biospecimen (for example, part of a blood sample that is left over after being drawn for clinical purposes), even if the investigator is not being given information that would enable him or her to identify whose biospecimen it is.”). However, this amendment would be prospective only. Researchers would still be permitted to use already-existing tissue samples without obtaining additional consent, so long as the researchers followed previously acceptable de-identification or anonymization procedures. *Id.* at 53,944 (“[T]he [proffered rule] proposes to have the new definition of human subject apply prospectively, that is, it will only apply to research involving biospecimens that will be collected in the future.”).

<sup>107</sup> *See* Federal Policy for the Protection of Human Subjects, 80 Fed. Reg. at 53,943 (conceding that, under the existing regulations, “provided the biospecimens and data were collected for purposes other than the currently proposed research, it is permissible for investigators to conduct research on biospecimens and data that have been stripped of all identifiers without obtaining consent because the non-identified biospecimens and data do not meet the regulatory definition of human subject”); *id.* (observing that many commenters to the Advanced Notice of Proposed Rulemaking opposed expanding the informed consent requirement to de-identifiable biospecimens due to the added time it would take to obtain consent). Currently, both the Common Rule and HIPAA provide straightforward routes for avoiding the need for informed consent through de-identification. *See* 45 C.F.R. § 164.514(b)(2)(i) (enumerating eighteen identifiers, removal of which renders what would otherwise be protected health information “de-identif[ed]” and outside the scope of the HIPAA Privacy Rule); OFFICE FOR HUMAN RESEARCH PROTS., *supra* note 17 (reaffirming that the review and consent obligations ordinarily applicable to federally funded research do not apply to research using biological specimens that are not “individually identifiable”). As set forth above, the proposed revisions to the Common Rule would eliminate this loophole to informed consent for federally funded human subjects research — at least with respect to subsequently generated research samples. *See supra* notes 17, 106. These revisions would not alter the scope of HIPAA’s Privacy Rule.

spleen was removed as part of his medical treatment.<sup>108</sup> Henrietta Lacks, whose cells gave rise to the first immortal cell line, similarly became a source for research materials without her knowledge or consent.<sup>109</sup> As an indigent African American woman in Baltimore, Lacks was a patient in the public wards, where physicians “often used patients . . . for research, usually without their knowledge. Many scientists believed that since patients were treated for free in the public wards, it was fair to use them as research subjects as a form of payment.”<sup>110</sup>

Nor is the use of human tissue for research without consent a thing of the past or an indignity visited only on the poor. Recent lawsuits have exposed researchers making use of thousands of stored human tissue samples without asking any permission from the sources of those samples. For instance, parents in Minnesota and Texas sued state officials for unlawfully retaining newborn blood cards indefinitely and sharing those tissue samples with outside research institutions and hospitals without parental knowledge or consent.<sup>111</sup> Consistent with the experiences of John Moore and Henrietta Lacks, these parents found themselves facing the uncontrolled use of private information about themselves and their children. State officials thought asking permission was simply unnecessary.

The use of these body products without consent may be troubling for dignitary, privacy, familial, and other reasons.<sup>112</sup> It may also raise more directly utilitarian harms. Patients may forego physician or other medical interactions out of fear that their cells will become fodder for research.<sup>113</sup> Moreover, while research unquestionably leads to significant societal advances, it may also inure to the detriment of the individuals from whom research specimens come. Research use of human cells without consent is often premised on their de-identification or anonymization. But such processes, and the status of tissue as

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<sup>108</sup> *Moore*, 793 P.2d at 480–83.

<sup>109</sup> See SKLOOT, *supra* note 53, at 29–33 (describing Lacks’s admission to the public ward at Johns Hopkins hospital for surgery, the limited consent form she signed, and the biopsy and delivery of her cervical cancer cells to a research lab).

<sup>110</sup> *Id.* at 29–30.

<sup>111</sup> See Complaint, *Beleno v. Tex. Dep’t of State Health Servs.*, No. 5:09-cv-0188 (W.D. Tex. Mar. 12, 2009); Complaint, *Bearder v. State*, No. 27-CV-09-5615 (Minn. Dist. Ct. Mar. 11, 2009). Under new federal law, parental consent must be obtained for the use of newborn blood cards for federally funded research. See Newborn Screening Saves Lives Reauthorization Act of 2014, Pub. L. No. 113-240, § 12, 128 Stat. 2851, 2857 (codified at 42 U.S.C. § 289 note (2012)).

<sup>112</sup> See, e.g., Ram, *supra* note 20, at 125–37 (identifying four types of concerns that tissue providers may hold: control, confidentiality, commercialization, and cure).

<sup>113</sup> *Id.* at 128–29 (collecting examples of individuals or communities who have avoided medical interactions and interventions due to fear of subsequent use of their cells for research without their consent).

anonymous, are far from certain.<sup>114</sup> At a minimum, where effective de-identification or anonymization cannot be accomplished, reliance on such tools to circumvent otherwise-applicable consent requirements exacerbates, rather than alleviates, the burdens of research participation.

To date, clinical conscription of human body products from living persons is rare, but the experience of the research biobank suggests further depths to which a refusal to acknowledge property rights in the progenitors of human tissue may descend. Troublingly, hints of commodification of body products without consent may already be apparent across the research-treatment divide. As set forth at the outset of this Review, medical schools in possession of cadavers may, and sometimes do, sell off bodies and body parts to other institutions.<sup>115</sup> In this way, modern medical practice parrots the consent-free approach of the research body bank. Medical schools or hospitals securing permission for one purpose may nonetheless use a body (or its parts) for another (revenue-generating) purpose.<sup>116</sup>

### CONCLUSION

Kara Swanson's *Banking on the Body* gives a rich history of how the United States ended up with blood and milk banks that could, but generally do not, pay the individuals who provide their wares. Her careful work tracing the origin and development of the body "bank" provides a useful lens for examining concepts of property in the body and who may assert such claims. And Swanson identifies historical evidence that contradicts the traditional narrative set forth for the

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<sup>114</sup> A number of recent studies have demonstrated that anonymization may not be achievable. In one demonstration, researchers showed that "an individual can be uniquely identified with access to just 75 single-nucleotide polymorphisms (SNPs) from that person," while "[g]enomewide association studies routinely use more than 100,000 SNPs to genotype individuals." McGuire & Gibbs, *supra* note 18, at 370; see also Melissa Gymrek et al., *Identifying Personal Genomes by Surname Inference*, 339 SCIENCE 321, 321 (2013) ("[W]e report that surnames can be recovered from personal genomes by profiling short tandem repeats on the Y chromosome (Y-STRs) and querying recreational genetic genealogy databases."). See generally Angela L. Morrison, Note, *A Research Revolution: Genetic Testing Consumers Become Research (and Privacy) Guinea Pigs*, 9 J. ON TELECOMM. & HIGH TECH. L. 573, 590-91 (2011) (describing multiple studies demonstrating that it is possible to identify individuals from anonymized DNA samples). Re-identification is possible even from pooled or aggregated DNA data. See Nils Homer et al., *Resolving Individuals Contributing Trace Amounts of DNA to Highly Complex Mixtures Using High-Density SNP Genotyping Microarrays*, PLOS GENETICS, Aug. 2008, art.1, 2-6.

<sup>115</sup> See *supra* note 4 and accompanying text.

<sup>116</sup> Presumed consent for cadaveric organ donation may raise issues distinct from the reallocation and sale of donated cadavers (or their parts) identified here. Under a presumed consent framework, the law "presumes that one is willing to be a donor unless a prior refusal has been recorded, or relatives have objected." Michele Goodwin, *Deconstructing Legislative Consent Law: Organ Taking, Racial Profiling & Distributive Justice*, 6 VA. J.L. & TECH. art. 2, ¶ 4 (2001). Where presumed consent is at issue, at a minimum, there is no substitution of a secondary use in place of a use for which affirmative consent was given.

downsides of paying people for their body products. Through her work, readers can check the factual accuracy of claims about the harms of providing payment for the raw materials for body-product exchange. Swanson's work should inspire other scholars to question whether the current body-banking system accurately reflects society's values, rather than just the circumstances of history. It is a volume well worth reading and learning from.

Yet Swanson's book takes up only pieces of the extensive scope of body banking, leaving largely unexplored the complementary experiences of biobanking human tissue or genetic information for research use. Given the sweep of Swanson's book, this omission is understandable, though unfortunate. Together with an analysis of research biobanking, Swanson's book makes plain that permitting every entity that interacts with body products to make money from doing so — except the sources of those products — disserves research and medical practices alike. Providing payment to the progenitors of body products, whether directly or through benefit sharing, need not result in denigration of the human body (or spirit) or in exploitation. Indeed, history indicates that providing remuneration may yield better access to better resources — and with better outcomes for all — whether for clinical or research use.

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