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Columns: Currents in Contemporary Bioethics

The Henrietta Lacks Case: Ongoing Litigation Seeks Closure

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Abstract

The litigation brought by the Estate of Henrietta Lacks against Thermo Fisher Scientific, Ultragenyx Pharmaceutical, and Novartis Pharmaceuticals reframes benefit-sharing from voluntary institutional ethics into an enforceable legal duty. By pleading a single equitable claim — unjust enrichment — the Estate seeks to bypass the property and informed-consent doctrines that have defeated comparable tissue-appropriation suits, while accepting distinctive risks involving remoteness, limitations, causation, and apportionment. This commentary examines the strategy's strengths and vulnerabilities through the still-pending Ultragenyx case, and considers its implications for research consent, prospective benefit-sharing frameworks, and bioethics pedagogy. Whether or not the remaining claim succeeds, the litigation has already altered the conversation about who should profit from human biological materials.

Keywords: informed consent; biobanking; unjust enrichment; tissue ownership; Henrietta Lacks

About This Column
The Currents in Contemporary Bioethics column features examinations of recent developments and trends in bioethics. If you would like to submit to this column, please contact JLME editor-in-chief Aaron Kesselheim at akesselheim@bwh.harvard.edu.

The litigation brought by the Estate of Henrietta Lacks marks a pivotal moment in the intersection of bioethics and private law: by pleading a single cause of action — unjust enrichment — the Estate has reframed benefit-sharing as an enforceable legal duty rather than a matter of voluntary institutional ethics. This strategy is designed to sidestep the barriers posed by property and informed-consent doctrines, yet it also presents distinctive doctrinal and practical vulnerabilities that future courts will have to confront. That two of three filed actions have already produced confidential settlements suggests defendants take the theory seriously; whether it produces durable precedent now turns on the still-pending litigation against Ultragenyx Pharmaceutical.[1]

From the development of the polio vaccine to exploring the effects of zero gravity in outer space, one would be hard-pressed to find an area of biomedical research that has not directly benefited from the HeLa cell line. In 1951, 31-year-old Henrietta Lacks was diagnosed with invasive cervical adenocarcinoma at the Johns Hopkins Hospital in Baltimore, Maryland. Redundant biopsies of her tumor and healthy cervical tissue were collected during her first radium treatment and sent to the laboratory of Dr. George Gey, who had spent the last three decades aiming to grow immortal human cells, i.e., cells that would continuously replenish themselves. The aforementioned biopsies were not medically indicated for Ms. Lacks' surgical care nor for her radium therapy. Notably, Ms. Lacks was not made aware of the fact that the tissue samples in question would be collected. Ms. Lacks' cells led to the creation of the first immortal human cell line, which was subsequently utilized for research, sold, and bought worldwide without the knowledge or consent of Ms. Lacks or her family.[2]

Decades after Ms. Lacks' death, her Estate has brought successive federal actions against Thermo Fisher Scientific, Ultragenyx Pharmaceutical, and Novartis Pharmaceuticals in the United States District Court for the District of Maryland, alleging unjust enrichment. The Thermo Fisher action, filed in 2021, settled on confidential terms in August 2023.[3] The Novartis action, filed in 2024, settled confidentially in early 2026.[4] The Ultragenyx action, filed in August 2023, remains pending and is the only case in which a court has issued a substantive ruling, denying Ultragenyx's motion to dismiss in May 2024.[5]

The deliberate confinement of the pleadings to a single equitable claim reflects the formidable doctrinal barriers that have frustrated plaintiffs in comparable tissue-appropriation cases. Most notably, the California Supreme Court's decision in *Moore v. Regents of the University of California* forecloses cell-ownership theories by holding that individuals retain no property interest in excised tissue.[6] Subsequent decisions, including *Greenberg v. Miami Children's Hospital Research Institute* and *Washington University v. Catalona*, have reinforced this position in the research-donation context.[7] Similarly, an informed-consent claim would founder on two obstacles: first, research-specific consent requirements did not exist in 1951; and second, any such duty would have run to the procuring physicians, not to downstream commercial actors.

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The enrichment theory, by contrast, capitalizes on equity's traditional willingness to disgorge profits obtained through wrongful acquisition. Its doctrinal strengths are twofold. First, the Estate contends that the theory avoids the property-rights impasse by focusing on defendants' ill-gotten gains rather than on the plaintiff's putative ownership. Whether unjust enrichment can serve as a freestanding cause of action — independent of an underlying tort or established property interest — remains a matter of scholarly debate and is itself contested in the Lacks litigation, with the Estate arguing for the freestanding view and defendants arguing that absent a tort or recognized property interest, no enrichment can be deemed "unjust." Second, the theory offers remedial flexibility: restitution can be calibrated to the demonstrable commercial value of HeLa-derived products while leaving courts discretion to establish injunctive control over future use.

The theory's vulnerabilities, however, are substantial. Defendants may argue that they were not the parties responsible for the original wrong: HeLa cells were freely distributed by George Gey and his collaborators decades ago and have been commercially available for generations. Ultragenyx pressed precisely this point in its motion to dismiss, contending that its acquisition and use of the cells is too remote from the 1951 seizure to support a claim for unjust enrichment.[8] Judge Boardman rejected that argument at the pleading stage, but the deeper question for equity courts — whether ongoing commercialization, undertaken with full knowledge of the cells' unethical origins, is itself unjust today, regardless of the norms that prevailed at the time of the original collection — remains live and will be tested as the litigation proceeds.

Temporal concerns further complicate matters. Maryland's three-year statute of limitations would ordinarily bar claims premised on commercialization that began decades ago. The Estate has invoked § 5-204 of Maryland's Courts and Judicial Proceedings Article, which denies the benefit of a limitations defense to foreign corporations conducting intrastate business in Maryland without having registered to do so. Ultragenyx challenged § 5-204 as a violation of the dormant Commerce Clause, prompting the Maryland Attorney General to intervene to defend the statute. In March 2025, the court rejected the constitutional challenge.[9] Whether the statute will ultimately defeat Ultragenyx's limitations defense, however, depends on a factual question reserved for later proceedings: whether Ultragenyx in fact conducted sufficient intrastate business in Maryland to fall within § 5-204's reach.

Causation and apportionment present additional obstacles. The value generated by HeLa cells now resides in a complex web of scientific labor, intellectual property, and capital investment. Downstream users — pharmaceutical manufacturers, clinicians, and ultimately patients — are many steps removed from the original nonconsensual biopsy. Determining which parties are within the equitable "zone" of liability, and what fraction of their profits should be attributed to the initial wrong, will test the limits of restitutionary accounting. The May 2024 order denying Ultragenyx's motion to dismiss suggests that, at least at the pleading stage, Maryland courts will entertain such claims.[10] Whether that openness survives discovery and expert valuation remains speculative.

The choice of forum underscores the Estate's strategic calibration. Maryland substantive law governs under diversity jurisdiction because the alleged wrong originated in Baltimore. While Maryland has not squarely addressed unjust enrichment claims based on the use of biological materials, it has not foreclosed them either — unlike jurisdictions such as California and Florida, where courts have rejected tort and restitution claims involving excised biological materials on the ground that individuals hold no legally protected property interest in those materials once removed from the body.

Should the Estate prevail in the pending Ultragenyx litigation, the implications would extend far beyond this case. A judicial finding that downstream commercial actors may owe restitution for unconsented tissue appropriation would place immediate pressure on research institutions, biobanks, and biotechnology companies to reconsider how human biological materials are obtained and governed. Even absent such a ruling, the suits, and the settlements they have already produced, signal that historical reliance on broad consent forms and the absence of ongoing obligations to tissue sources may no longer be ethically or strategically sustainable.

For current research practice, the litigation highlights the limits of one-time consent models. Since 2019, the Common Rule has required consent forms for research involving identifiable biospecimens to state whether those specimens may be used for commercial profit and whether the participant will share in such profit.[11] In practice, this requirement is typically satisfied by a brief statement that commercial use is possible and that participants will not share in proceeds — a disclosure that arguably normalizes the very dynamic the Lacks litigation calls into question. A Lacks-informed approach would treat such disclosures as a floor rather than a ceiling. It would consider whether participants should receive more specific information about how their materials may be commercialized, by whom, and through what kinds of partnerships, and whether legally sufficient consent under federal regulation exhausts the institution's ethical obligations to those whose biospecimens generate substantial commercial value.

The litigation also revives the practical question of benefit-sharing. Benefit-sharing need not require royalty payments to every tissue contributor, an administratively implausible model. Within the United States, prospective benefit-sharing frameworks remain uncommon, but several precedents demonstrate what they can look like. PXE International, a patient advocacy group for pseudoxanthoma elasticum, co-holds the patent on the ABCC6 gene identified through samples its community provided and shares in royalties from derived diagnostic tests — an arrangement negotiated prospectively as a condition of community participation in the research.[12] The Havasupai Tribe's 2010 settlement with Arizona State University, though remedial rather than prospective, illustrates the components such an arrangement can include: financial compensation, return of samples, and ongoing institutional commitments to community priorities including scholarships and clinic support.[13] More common are governance arrangements, such as tribal review processes for research involving Native communities, or community advisory boards at academic biobanks, through which donor communities exercise oversight without necessarily sharing in commercial proceeds. Each of these models demonstrates that meaningful community returns can be operationalized, whether through equity, royalties, services, or institutional commitments. The central lesson is that institutions may be better served by designing prospective benefit-sharing frameworks voluntarily than by having remedial structures imposed through litigation.

The cases likewise carry pedagogical significance. The story of Henrietta Lacks is often taught as a mid-twentieth-century failure of informed consent corrected by later research regulations. The Estate's unjust enrichment theory reframes that narrative. It suggests that the core issue was never only disclosure at the moment of tissue collection, but also the enduring allocation of value created from human biological materials. A curriculum that takes this reframing seriously would situate the Lacks case not within the consent unit alone, but within a sequence on the legal

status of human biological materials, alongside *Moore*, *Greenberg*, and *Catalona*, allowing students to see how the same kinds of facts give rise to distinct legal theories with markedly different remedial implications. Teaching the Lacks case solely as a historical episode in the evolution of informed consent risks obscuring unresolved contemporary questions about ownership, fairness, and commercialization that remain central to genomic research and precision medicine — questions that current students will confront as researchers, clinicians, IRB members, and institutional leaders.

In sum, the Lacks litigation invites an ethical and legal reckoning with a harm long acknowledged but rarely redressed. By framing benefit-sharing through unjust enrichment, the Estate challenges courts, and the biomedical enterprise more broadly, to treat fairness not as an aspirational principle, but as a governance obligation. Whether or not the remaining claim ultimately succeeds, the litigation has already altered the conversation about who should profit from the products of human biology.

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