

‘Do We Own Our Bodily Tissues?’

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May 2 marks the final event in the Exploring Ethics Forum: The Henrietta Lacks Series, a nine-month-long series run by the San Diego’s Center for Ethics in Science and Technology as part of the citywide event, The Henrietta Lacks Project. Along with numerous other events held by academic institutes across San Diego as part of The Henrietta Lacks Project, The Henrietta Lacks Series has been exploring ethical issues through the lens of Rebecca’s Skloot’s best-selling novel “The Immortal Life of Henrietta Lacks.”

Over the past nine months, the San Diego community has considered a wide array of controversial ethical questions examined in Skloot’s book from [donor informed consent](#) and protection of vulnerable populations in scientific research to the [commercialization](#) and the [religious implications](#) of “immortal” cell lines.

Central to all of these issues is the basic question: “Do we own our bodily tissues?” If our tissues are our property in the same way as our cars and houses then it seems clear that our tissues should not be taken from us without our consent or used in any way that we have not agreed to and that we should get a share or at least some form of compensation when profits are made from the use of our tissues. If someone takes our material possessions, it is considered theft or grounds for a civil action for conversion. However, when it comes to our tissues, our rights are less clear.

In the U.S., we have a fundamental right to privacy that protects our right to control our bodies. This is a broad right that includes the right to refuse medical care and the right to procreate. However, while our society holds sacred an individual’s right in his/her body, the same rights are not recognized

for an individual's tissues. Once tissues or cells are removed from our bodies, they are no longer afforded the same protection.

What is the reason for this distinction? Is it the mere fact that tissue samples are separated and thus technically no longer part of our bodies? Or is that these samples provide endless potential value to scientific and medical breakthroughs and that extending the right to privacy to these samples would seriously stifle such progress? Without access to HeLa cells (the immortal cell line created from Henrietta Lack's tissues) innumerable crucial scientific discoveries, such as the number of human chromosomes, and essential medical treatments, such as the polio vaccine, would have been substantially delayed or in some cases would never have been possible.

An interesting examination of the question of tissue donor rights is provided in the 2006 case of *Washington University v. Catalona* (437 F. Supp. 2d 985 (E.D. Mo. 2006), *aff'd*, 490 F.3d 667 (8th Cir 2007), *cert. denied*, 128 S. Ct. 1122 (2008)). [This case](#) is particularly interesting as the court considers the issue of tissue donors' ownership rights apart from the complicating factors of deception or commercial gain that often color the facts in other cases involving donor rights.

In this case, William Catalona, a leader in the field of prostate cancer research and employee of Washington University, collected samples from his prostate cancer patients to form a bio-repository of samples for use in prostate cancer research. At the time of donation, all of the donors signed a consent form indicating that they were making a free and generous donation and that they could not "claim ownership rights" to any medical or scientific product that results from research with the sample. When Catalona left Washington University for a new position at Northwestern University, he sought the consent of his patients for the release of the samples to him for use in further research at Northwestern. As a result, Washington University, believing that the samples belonged to them, sought a declaratory judgment to determine ownership of the samples.

Catalona was joined by several of his patients as defendants in the case. They argued that the patients donated their samples with the intent that Catalona would retain the samples and that they did not intend to make a gift of the samples to Washington University or for the university to have ownership of the samples. They argued that the subsequent consent form signed by the patients agreeing to release the sample to Catalona clearly demonstrated the patients' wishes. However the court found that, in light of the wording of the original informed consent form and the circumstances surrounding the donation, the patients had made a gift of the samples to the university. The court also noted that as the samples were at all times in the exclusive possession and control of Washington University, it had ownership over the samples.

Of particular interest in this case, is the court's comments on the potential "public policy" ramifications of the position of Catalona and his patients. [The court noted:](#)

Medical research can only advance if access to these materials to the scientific community is not thwarted by private agendas. If left unregulated and to the whims of a RP (research participant), these highly-prized biological materials would become nothing more than chattel going to the highest bidder. It would no longer be a question of the importance of the research protocol to public health, but rather who can pay the most. Selling excised tissue or DNA on E-Bay would become as commonplace as selling your old television on E-Bay. The integrity and utility of all biorepositories would be seriously threatened if RPs could move their samples from institution to institution any time they wanted. No longer could research protocols rely on aggregate collections since individual samples would come and go. Accountability would no longer exist since institutions would merely be warehouses filling purchase orders.

More alarming is the great potential for prejudicial influences into medical research. Allowing an RP to choose who can have the sample, where the sample will be stored, and/or how the sample can be used is tantamount to a blood donor being able to dictate that his/her blood can only be transfused into a person of a certain ethnic background, or a donated kidney being transplanted only into a woman or man. This kind of "selectiveness" is repugnant to any ethical code which promotes medical research to help all of mankind.

While the court raises some interesting points, the court did recognize the patients' right to withdraw their consent at any time allowing for their tissues to be identified and destroyed. Thus, following donation and the initial informed consent, a patient has the right to withdraw his/her tissues from a study completely but not the right to further stipulate how those samples can be used.

As with many bio-ethical issues, the problem with defining tissue donors' ownership rights lays in the difficulty of determining the right balance between protecting patients' rights and protecting scientific and medical progress. This balance was not achieved in the 1950s when Henrietta Lacks' cells were taken from her and, as demonstrated from the recent Catalonia case, remains a contentious issue today.

While the proper balance may not be clear, what is certain is that scientists and society continue to face the ethical issues examined in "The Immortal Life of Henrietta Lacks" and the underlying question of tissue donor ownership rights. As lawmakers continue to grapple with these difficult ethical problems, the awareness and participation of the public will be an essential if a proper balance is ever to be found.