

# **THE GLOBAL BODY MARKET**

**Altruism's Limits**

**Edited by Michele Goodwin**

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ALTRUISM'S LIMITS

Edited by

**MICHELE GOODWIN**

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Professor of Medicine & Public Health  
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## THE GLOBAL BODY MARKET

The dark side of body part trading operates in a dynamic fashion, full of mystery, intrigue, and ambition. On the one hand, black and gray markets are illegal, but also pioneering and inventive; and although this type of criminal activity requires a level of dexterity and innovation, the point should not be lost that these markets thrive and flourish, sometimes in view of law. On the other hand, altruistic body part procurement is mired by low participation, which encourages black market transactions. Thousands of sick patients will die each year without the hope of receiving an organ or bone marrow donation through the altruistic procurement system, so they turn to the dark side.

This book offers a frank conversation about altruism in the global body market. It exposes how researchers exploit their patients' ignorance to harvest tissue samples, blood, and other biologics without consent for research and patent development. The book chronicles exploitation in the name of altruism, including the nonconsensual use of children in dangerous clinical trials, and analyzes social and legal commitments to the value of altruism – offering an important critique of the vulnerability of altruism to corruption, coercion, pressure, and other negative externalities.

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*For Sage and Brooks*

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forward to relieve the strain in the nation's organ transplantation system. That it has been nearly thirty years since Congress last took up organ transplantation policy in more comprehensive terms indicates how long overdue a meaningful dialogue remains.

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Finally, for a book positing *altruism's limits*, there is a subtle irony in closing my acknowledgments by thanking my family for their selflessness, support, kindness, and consideration. I am inspired by and ever grateful to them. I mark the growth, travels, and development of my children by their accomplishments as well as each of my book projects. As I finalize this book, Sage completes a first semester in college after a year in China and Brooks nears the end of his time at Fletcher, after a successful summer in Thailand. Their accomplishments place everything that their parents achieve in context as too often what we do pales in comparison. And to my husband, Gregory Shaffer, thank you for knowing what work is, for recognizing it, embracing it, and giving so very much with an indomitable kindness of spirit and soul.

# The Global Body Market: Altruism's Limits

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(U.S. Public Health Service; Tuskegee University Archives)

Eighty years ago a medical study, commonly referred to as the "Tuskegee Study," engaged hundreds of poor black farmers and day laborers in a human research project focused on their deaths from syphilis. The participants were syphilitic and many were sexually active with their wives, who later became infected. During the forty years that the study was conducted, treatments to cure the clinical trial subjects were withheld from them. Instead, under the guise of treatment, they were provided aspirin and subjected to painful spinal taps. Most interesting, however, are the dynamics and interplay of altruism. The U.S. Public Health Service and researchers involved emphasized that what the human subjects received was "special and *free*." The research subjects were problematically portrayed as altruistic, rather than coerced and vulnerable. This book addresses these problematic framings.



# Introduction

Michele Goodwin

There exists both the public and private negotiation processes for body part transactions, and both systems operate at crisis levels. These systems are characterized by incoherence, ambiguity, and sometimes fraud, coercion, clandestineness, and opportunity. Even more perniciously, there are black market transactions in the human body that involve direct exploitation, slavery, and even murder. Such are the scale and scope of the human body trade.

On one end of the spectrum exists an altruistic vision for human body part exchange, whether for organs, bone marrow, ova, sperm, corneas, heart valves, bones, or other highly profitable body parts. At the other end operate cold realities: medical school chop shops selling off abandoned and donated parts; creepy, mafialike organizations that sweep in after disasters like the tsunamis in Thailand and Japan or the devastating earthquake in Haiti to rob from the dead; rabbis hustling organs – conscripting poor Israelis to surrender kidneys for so-called cousins in the United States; and desperate delicensed doctors who figure the best way to make money these days is to open a biobank – and steal deceased persons' organs. These are the dark secrets of body part trading: hungry mafias taking while they can.

The dark side of body part trading operates in a dynamic fashion, full of mystery, intrigue, and ambition. On the one hand, black and gray markets are illegal, but also pioneering and inventive. It may be argued that criminal activity requires a level of dexterity and innovation. However, the point should not be lost; black and gray body part markets thrive and flourish, sometimes in view of law. Indeed, biobank companies often directly flout the rule of law.

On the other hand, our altruistic system of procurement is sadly predictable and quite conventional. For example, today we know that thousands of sick patients will die without the hope of ever receiving an organ or bone marrow donation. End-stage renal failure patients – those in need of kidneys – are the unfortunate victims in a system that demands altruism from any and all who will consider saving their lives. Only recently, in *Flynn v. Holder*, did the Ninth Circuit carve out an exception for bone marrow patients. In other words, as of 2012, those in need of bone marrow are no longer harnessed to a procurement scheme that necessitates altruism only; their donors may be compensated or receive a gift or some form of incentive as a reward for donating. The United States Justice Department threatens to appeal.

Predictably, the transplant waiting list will expand far beyond the capacity of organ donors to ever meet the demand. You might consider what this all means after a “gift of life” public service announcement airs on your local television station. Within the span of your favorite one-hour television show, a candidate on our organ transplant waiting list will likely die. Commentators are divided as to how this issue should be addressed. To change the altruistic procurement system by introducing market alternatives may ultimately lead to placing values on products from the body, thereby interfering with important societal notions of personhood according to Professor Margaret Radin. Acquiescence to an altruistic system of procurement might necessarily mean accepting its failures to generate an adequate supply of organs and the avoidable deaths that result.

In either case, formal law has yet to catch up with these new malleable biotechnological regimes, which operate both within the public sphere and underground. The public process is best characterized by our current organ procurement and allocation systems, which are regulated by Congress through the National Organ Transplantation Act (NOTA) and at the state level through the Uniform Anatomical Gift Act. However, those systems, relying upon pure altruistic transfers, are underserved and oversubscribed. Quite bluntly, demand for precious body parts – corneas, kidneys, hearts, lungs, livers, and the like – far outpaces altruistic supply. The private, underground systems involve individuals taking their chances on buying an organ through the black market and companies buying and selling human body parts and tissues from university hospitals, funeral homes, and organ procurement organizations.

These contemporary scenarios raise a multitude of issues, including the ethics of financial incentives in supplying resources from the body, the role of law in shaping the contours of body part exchanges, the limits of autonomy, the breadth of legitimate contractual agreements, morality, responsibility, and conflicts of interests. The strange narratives associated with body part corruption are animated by the tremendous demand for human biological supply and suppliers resorting to crafty – and often clandestine – measures to procure them. With more than one million allograft surgeries taking place each year in the United States, supply must come from somewhere.

Yet, recent body part scandals obscure the other contested and equally commoditized spaces mapped on the human body. Wombs, ova, sperm, embryos, and children represent the publicly marketized end of the spectrum. At this end of the scale, the essences of life – the building blocks – become regularly and intensely subjected to market norms. What contributes to the differences in how these spheres (organs vs. ova and the like) are perceived in society, regulated by legislatures, or adjudicated by the judiciary is conditioned by perceptions and normative understandings of the human body.

Quite restrictively, NOTA prohibits any “valuable consideration” to be exchanged for human tissues. Despite this broad language, reproductive markets flourish in direct view of the Justice Department. The law, crafted by Senator Al Gore in 1984, reflects a biotechnologically bygone era that predates robust ova and sperm markets, billion-dollar tissue markets, and the grave disparity between organ supply and demand in the United States and worldwide.

*The Global Body Market: Altruism's Limits* reaches beyond asking what is appropriately commodifiable and what is not. Those questions are important but fall short of a nuanced engagement on commensurability and altruism. The book considers the tremendous demands for substances like organs, ova, sperm, and other biological materials as well as information demands that can only be satisfied by rigorous research and analysis. Importantly, this book does not abandon legal pragmatism in search of a theory. Instead, the analysis breaks ground by taking a legal realism approach to study the history of body part transactions and then turns to the necessary conditions for a market in contestable commodities. The chapters vary by subject matter, casting a broad net querying the function

of altruism and markets across a spectrum, encompassing organ commodification and baby markets to patents based on cell lines and tissues for research.

## The Framework

*The Global Body Market* does not attempt to prove that black markets exist in human biological supply. Rather, this book is the next step. It considers how we should think about the markets that currently exist and what we should do about them. To accomplish this, I have enlisted experts in contracts, criminal law, tax law, trusts and estates, tort law, and property law, among others, to contribute to this important dialogue. The contributors consider how we might begin to create frameworks that move the discussion about incentives for human biological materials beyond hypothetical treatments in the literature to test them at the state and federal levels.

The book offers an important analytical framework for regulating markets in the human biological domain, thus distinguishing it from socio-legal accounts of the topic in recent years that call attention to human markets without offering a normative view. It analyzes demand and supply of human biologics by taking into account the need for law, the demands of biotechnology, and the role of bioethics. We do not debate whether there should be markets in the human biological sphere. Rather, we acknowledge body markets as a global phenomenon and probe how we should think about public and private regulations of body markets. Thus, we move beyond attempting to call public attention to rogue operations involving human body parts to interrogating the rule and role of law when body markets emerge.

*The Global Body Market* contributes to an emerging social discourse on the human body exchange in five distinct ways. First, it expands the conventional bioethics framework to include an examination of markets in human biological supply – an issue marginally explored by traditional bioethics scholarship. Second, it adds cultural value to bioethics and biotechnology scholarship by taking seriously the emerging discourses of race, socioeconomics, and politics in bioethics. Third, it engages tort law, articulating why a civil remedies approach should serve as a viable vehicle for redressing harms suffered by consumers of human biological supplies. Surprisingly, in the realm of human body politics, tort law is a spotty patchwork. For

example, in some instances plaintiffs who claim that their (or a relative's) body parts were “stolen” by doctors and researchers can recover damages, and in other cases they cannot. In some instances those who have been harmed by the implantation of unhealthy human tissue can recover, while again others are without a remedy. The chapter entitled *Liberalizing Tort Law* critiques the judicial formalism that ultimately constrains the development of judicial frameworks to reorient legal consideration of body part claims. Fourth, this book engages criminal and tax law, shaping a prospective view of public regulation of human biological exchanges. The chapters on criminal law and tax law regimes provide compelling, original scholarship, which defines how policy makers should “police” human biological exchanges. Fifth, in *Situated Bodies in Medicine and Research*, Naomi N. Duke warns that those most likely to be harmed by judicial formalism and a blind adherence to altruism will be poor people of color.

This book examines a blind spot in the broader literature on the human body and its uses in the marketplace, medicine, and society. Authors in this volume urge a more nuanced approach to considering human biological exchanges. That is, they make the case that social justice, morality, and important sociolegal values do not derive exclusively from altruism. For example, a legal and social literature has developed, which associates commensurability and alienability in the human body with devaluing personhood, repugnance, and even claims that compensating people for organ sharing amounts to prostitution. Quite often, racial and economic statuses are deployed to argue that alienability or markets particularly hurt minorities. Assumed in this are the vulnerability and lack of capability (or incapacity) of the poor and people of color to steer themselves effectively out of the reach of hungry body “commodifiers” or brokers who seek to coerce and exploit them for their body parts. Such heuristics condemn all nonaltruistic body part exchanges as tainted by money or property exchanges.

Yet, altruism is corruptible, vulnerable to coercion, pressure, and threat. Indeed, that which is “free” does not always correlate to nor uphold foundational human values, such as honesty, love, compassion, integrity, dignity, empathy, respect, freedom, liberty, and dignity. Slavery remains the starkest example of that. However, one need not extend back to slavery in order to parse out the limits of altruism.

*The Global Body Market* avoids positioning and patronizing marginalized groups as “objects” within the broader discourse of human biological