

<http://somatosphere.net/?p=14170>

Special Issue! The Human, Human Rights, and DNA Identity Tests

2018-01-31 23:45:13

By Anna Zogas

In addition to the articles highlighted in [this month's regular "In the Journals" post](#), the January issue of [Science, Technology, & Human Values](#) is a themed issue on "The Human, Human Rights, and DNA Identity Tests." In the introductory article, Noa Vaisman writes that the papers "offer a serious challenge to the vision of the human subject at the root of human rights law." Here are the abstracts.

[The Human, Human Rights, and DNA Identity Tests](#)

Noa Vaisman

This special issue examines the diverse realities created by the intersection of emerging technologies, new scientific knowledge, and the human being. It engages with two key questions: how is the human being shaped and constructed in new ways through advances in science and technology? and how might these new ways of imagining the subject shape present and future human rights law and practice? The papers examine a variety of scientific technologies—personalized medicine and organ transplant, mitochondrial DNA replacement, and scaffolds and regenerative medicine—and their implications for our conceptualization of the human subject. Each is then followed by a commentary that both brings to light new dimensions of the original paper and presents a new theoretical take on the topic. Together these papers offer a serious challenge to the vision of the human subject at the root of human rights law. Instead of the autonomous, rational, unique, and physically discrete individual who owns herself and her body, the subject that emerges from the human technology assemblage has physically porous boundaries and a relational self. This depiction of the human being as a relational subject enmeshed in her technoscientific environment requires that we reconceptualize human rights law and practice.

[The "We" in the "Me": Solidarity and Health Care in the Era of Personalized Medicine](#)

Barbara Prainsack

This article challenges a key tacit assumption underpinning legal and ethical instruments in health care, namely, that people are ideally

bounded, independent, and often also strategically rational individuals. Such an understanding of personhood has been criticized within feminist and other critical scholarship as being unfit to capture the deeply relational nature of human beings. In the field of medicine, however, it also causes tangible problems. I propose that a solidarity-based perspective entails a relational approach and as such helps to formulate new solutions to complex ethical and regulatory questions, ranging from caring for people at the end of their lives to improving policies for organ donation and better governance of health data. It also underscores the importance of universal health care. Although a solidarity-based perspective does not require health to be seen as an individually enforceable right, it does influence our understanding of individual rights: it draws attention to how their meaning is shaped by shared social practices. I conclude by arguing that, in light of current pressures for medicine to become more personalized, using a relational understanding of personhood to shape policies and practices is a much needed endeavor.

[A “We” Problem for Bioethics and the Social Sciences: A Response to Barbara Prainsack](#)

Bob Simpson

In her article “The ‘We’ in the Me: Solidarity in the Era of Personalized Medicine,” Barbara Prainsack develops an earlier interest in the relationship between solidarity and autonomy and the way that these notions operate once passed through the lens of bioethical thought and practice. In his response to this article, Simpson introduces the perspective of two South Asian physicians on these issues. The piece highlights issues of personhood upon which the informed consent transaction is based and draws attention to the culturally specific versions of how people conceive of relationality, duty, care, and the obligations they feel they owe to others. The piece highlights the pronomial shifts between the “we” and the “me” and the way that these dispositions emerge in sociopolitically configured spaces. By paying careful attention to the settings and situations in which the movements between different positions actually take place, the ways in which the fabric of ethical life is made rather than simply given is revealed. Ethnographic inquiry is seen as crucial in understanding this process because it points to disjunctions between the categories that we are provided to apprehend the world and what it is actually like to live in that world.

[It Is Just a “Battery”: “Right” to Know in Mitochondrial Replacement](#)

Ilke Turkmendag

This article addresses the child’s right to know their genetic origins in mitochondrial donation. It focuses on the UK’s public debate on mitochondrial replacement techniques and examines the claims-making

activities that shaped the donor information regulations. During the public consultation, downplaying the significance of the mitochondria helped distinguish mitochondria donors from gamete donors and determine their relational status with the resulting child. As a result, according to the Mitochondrial Donation regulations, mitochondria donors, unlike gamete donors, will not be required to be identifiable to the resulting child. I argue that, in the UK, similar to donor conception, public understanding of mitochondrial donation is shaped by a “calculus of genes”: simplified accounts of how genes determine the resulting child’s characteristics and identity. While the donor conception regulations ascribe social meaning to the passage of genes, the mitochondria regulations strip the social meaning away from the donation based on the assumption that the genetic contribution made by the donor is quantitatively insignificant in influencing the identity of the resultant offspring. The nature of the genetic material itself should not be considered as a privileged standpoint from which to decide on social meaning of the donation or the rights attached to it.

[The mtDNA of Human Rights](#)

Benedict Douglas

Mitochondrial replacement therapy is a process whereby a child is created by combining the nuclear DNA of two people wishing to have a child with mitochondrial DNA (mtDNA) donated by a third person. It poses a new question as to the extent of a person’s right to know the identity of those from whom their DNA is inherited. In commentary upon Turkmendag’s paper, I evaluate the consistency of UK regulation of this issue with the European Convention of Human Rights. Under UK law, a person created using donated mtDNA is only entitled to information about the procedure which does not identify the donor. I argue that this approach is consistent with the previous European Court of Human Rights and UK judicial decisions on the rights of individuals to information about their identity and ancestry and with the deeper foundational principle which Kai Möller argues the Convention protects existential self-understanding. I conclude that, as mtDNA has not been proven to affect an individual’s life choices and outward characteristics to the extent that gamete donation does, it is acceptable to prioritize the interests that anonymous donation protects over the desire of the recipient to know the identity of their donor.

[The Social Life of “Scaffolds”: Examining Human Rights in Regenerative Medicine](#)

Bronwyn Parry

Technologies for enhancement of the human body historically have taken the form of an apparatus: a technological device inserted in, or appended to, the human body. The margins of these devices were clearly discernible

and materially circumscribed, allowing the distinction between the corporeality of the human body and the “machine” to remain both ontologically and materially secure. This dualism has performed some important work for human rights theorists, regulators, and policy makers, enabling each to imagine they can establish where the human ends and the other begins. New regenerative products such as Infuse™ and Amplify™ subsist, as animal-derived scaffolds seeded with growth hormone implanted within a prosthetic device. They are much more materially complex, and their identities thus remain open to contestation. Following Lochlann Jain’s 2006 work, I thus attend closely to their social lives, particularly the stories that are told about them and how these are employed to construct understandings of what kind of a phenomenon they are: systemic drug, biologic, or combinatorial medical device. The significance of this classificatory project is revealed in the final section of this paper, which explores how these stories shape understandings of “product failure,” liability, and causation when such products overflow their material and ontological categorization and their recipients become disturbingly “more than human.”

[Regenerating Bodies](#)

Michael Fisch

This article is an expanded commentary on the essay “The Social Life of ‘Scaffolds’: Examining Human Rights in Regenerative Medicine.” In discussing the limits and possibilities of the essay, this commentary suggests that problematizing scaffolds in regenerative medicine as a kind of infrastructure rather than prosthetic opens the way for an understanding of the genesis of regenerative assemblages in ways that help to reframe inherent issues of human rights. Ultimately, it proposes the notion of experimental ecologies as a way of thinking about an ethically driven productive entanglement of bodies, environments, and technology.

[Human Rights and New Horizons? Thoughts toward a New Juridical Ontology](#)

Anna Grear

The much-lamented anthropocentrism of human rights is misleading. Human rights anthropocentrism is radically attenuated and reflects persistent patterns of intra- and interspecies injustice and binary subject–object relations inapt for twenty-first-century crises and posthuman complexities. This article explores the possibility of reimagining the “human” of human rights in the light of anti- and post-Cartesian analyses drawing—in particular—upon Merleau-Ponty and on new materialism. This article also seeks to reimagine human rights themselves as responsabilized, injustice-sensitive claim concepts emerging in the “midst of” lively materialities and the uneven global dynamics of

twenty-first-century predicaments.

AMA citation

Zogas A. Special Issue! The Human, Human Rights, and DNA Identity Tests. *Somatosphere*. 2018. Available at: <http://somatosphere.net/?p=14170>. Accessed February 1, 2018.

APA citation

Zogas, Anna. (2018). *Special Issue! The Human, Human Rights, and DNA Identity Tests*. Retrieved February 1, 2018, from Somatosphere Web site: <http://somatosphere.net/?p=14170>

Chicago citation

Zogas, Anna. 2018. Special Issue! The Human, Human Rights, and DNA Identity Tests. *Somatosphere*. <http://somatosphere.net/?p=14170> (accessed February 1, 2018).

Harvard citation

Zogas, A 2018, *Special Issue! The Human, Human Rights, and DNA Identity Tests*, Somatosphere. Retrieved February 1, 2018, from <<http://somatosphere.net/?p=14170>>

MLA citation

Zogas, Anna. "Special Issue! The Human, Human Rights, and DNA Identity Tests." 31 Jan. 2018. *Somatosphere*. Accessed 1 Feb. 2018.<<http://somatosphere.net/?p=14170>>