



People's Science: bodies and rights on the stem cell frontier

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liberal autonomy and risk management, respectively. And Kaushik Sunder Rajan, in a provocative essay, argues that different positions held by the USA and India in the structure of international capital have produced vastly different modes of biomedical subjectivity in those two nations.

Reframing rights is also unique in its exploration of new forums and forms of civic engagement in the genetic age. The ongoing emergence of “genetic citizenship,” to use Jasanoff’s useful phrase, is evident in Robert Doubleday and Bryan Wynne’s chapter on British public engagement with environmental and biotechnological controversies. Wynne and Doubleday discuss the novel forms this engagement has taken – for example, quasi-democratic citizen participation within the internal processes of the Unilever Corporation – and the tension between the “despotic” and “democratic” tendencies of the British state that it has exposed. Meanwhile, Jenny Reardon’s critical account of the HapMap and Diversity Project initiatives, and specifically their attempts to create collective rights for genomically defined populations, reminds us that such initiatives will inevitably end in disarray if they overlook the inherent ethical content of the process of science itself. Finally, Jim Dratwa draws on European legislative history to illustrate the precautionary principle’s role as an “instrument of social imagination,” reminding legislators to consider the impacts of their regulatory actions on those unable to directly articulate rights and demands.

Collectively, the authors of this timely volume vividly depict a process of change extending to the very foundations of social order – one that can indeed be called *bioconstitutional*. At a time when our legal, social, and even natural categories appear most brittle, *Reframing rights* brims over with insight and guidance. Highly accessible, well researched, and edited with care, it is essential reading for anyone working at the intersection of law, science, technology, and culture.

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People’s Science: bodies and rights on the stem cell frontier, by Ruha Benjamin, Palo Alto, CA, Stanford University Press, 2013, 272 pp., \$76.50 (hardcover), ISBN 978-0804782975

This book examines the relationship between science and society by taking the example of how “the people” of a people’s science are either included or excluded in California Proposition 71. Early in the introduction, Benjamin quotes scholar-activist Patricia Berne as a reference point for the critical issues discussed in her book: “Before we start designing ways to get to the moon, can we just make

sure everybody on my block can actually get to work?” (1). This quotation is transformed into her own question at the end of the book: “What [does] a ‘right to stem cell research’ [mean] in a context in which basic healthcare access is not yet a guaranteed right in the United States?” (157). In the pages between these two questions, Benjamin uses “bioconstitutionalism” as a framework to unfold the various tensions between biomedical innovation and socioeconomic disparities in California’s three-billion-dollar investment on stem cell research over 10 years, also tackling the bioconstitutional struggles over the controversial field. She proposes the approach of “Sankofa science in action” to science-making. That is, we need to learn from history in order to build a future that exhibits social justice and health equity.

Methodologically, Benjamin uses qualitative research methods, uniting multisited ethnography of the California Stem Cell Research and Cures Initiative (hereafter the Initiative) from 2005 to 2007; interviews with physicians, patient families, and medical staff; personal conversations with those actively engaged in the biomedical, regulatory, and civic arenas of the Initiative; and document and media analysis.

Six chapters follow the preface and introduction. Chapter 1 shows how the “wrong” kind of publics, usually the “undesired” publics in subordinate social groups (feminist, disability, racial, etc.) were intentionally excluded from participation, while the “right” kind of publics, the stem cell supporters, were engaged in the decision-making of the Initiative. Chapter 2 presents three examples in which disability activists and stem cell advocates frame their concerns as a social versus a medical model of disability and disease, respectively (59). The former are worried about their social inequality, such as social exclusion, cultural stigma, and the lack of basic civil rights. The latter tend to emphasize the need for stem cell research and regenerative medicine to speed the invention of cures for patients. Chapter 3 discusses competing feminist framings of egg donor compensation policy, and the implications of California stem cell agency’s tightening and then loosening of restrictions on egg donation. Benjamin suggests that the change in the compensation policy reflects “the liberal notion of the individual rights” to both support and oppose compensation, and “the stratification and racialization of egg donors” (111).

Chapter 4 expands the terrain to hematopoietic stem cells for sickle cell disease, which used to commonly afflict African-Americans in the USA. It explains “socially produced ambivalence” as the main cause of why African-American patient families who had no access to quality healthcare nevertheless resisted being research subjects in experimental medicine. Chapter 5 depicts stem cell researchers’ approaches to including ethnoracial minorities in order to develop a diverse stock of stem cell lines. It contests the view that the minorities’ distrust in stem cell research is the root of their refusal and resistance to participation, arguing that we should instead shift the focus to the “trustworthiness of institutions.” The last chapter reinforces the problems of the politics of differences in the inclusion of the consenting publics for the Initiative, and outlines “real utopias” for participatory science-making.

Some stem cell opponents may respond favorably to this book, which articulates clear arguments for their position. Meanwhile, some stem cell supporters may find portions of the author's judgments unconvincing. For example, Benjamin holds that too much money is invested in the Initiative, mainly to the benefit of elites, whereas even basic healthcare access remains unguaranteed for lower socioeconomic groups. Stem cell supporters may argue that cutting the stem cell research budget in California cannot guarantee that the government will instead direct that money to improve basic healthcare in the state. Furthermore, the inequalities for minorities in US society did not originate with biomedical research, so the real target for eliminating those inequalities – at least in terms of healthcare – has to be providing better (and affordable) healthcare services for the disadvantaged groups. If we take a Sankofa-like approach and review the history of medicine, we might hope, with some good reason, that new biomedical research in the long run will benefit all people, regardless of the socioeconomic status.

Overall, this book is quite informative about the process of social inclusion and exclusion of public in California and provides the first detailed account of the scientific and political experiments behind Proposition 71. Benjamin reveals to readers the stories of those whose social and political lives may have been “ignored, dismissed, or misunderstood” (xiii). It contributes richly to the studies of science and society, participatory governance, race-ethnicity, and biological citizenship.

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Regenerating Bodies – tissue and cell therapies in the twenty-first century, by Julie Kent, London, Routledge, 2012, 217 pp., £90 (hardcover); £24.99 (paperback), ISBN 978-1-138-02011-5

Regenerating Bodies is essentially a book of two halves, with the first few chapters giving a useful overview of the regenerative medicine field, the regulation of the stem cell field in the UK and Europe, and introducing the skin cells case study. The later chapters in contrast focus much more on a feminist perspective of tissue use and the role of women's labor in regenerative medicine.

Chapter 1 starts with an overview of the emerging bioeconomies and the engineering of tissues for regenerative medicine, culminating in a case study of growing skin cells for cell grafts. Chapter 2 moves on to discuss regenerative medicine as a potential paradigm shift, including the role of new institutions such as the UK Stem Cell Bank. This then moves into a discussion of tissue and cell-based therapies in