

Fair Access to Stem Cells

By SUZANNE HOLLAND

While a great deal has been written about the moral status of the early embryo, comparatively little has been written about larger issues of social justice within which stem cell research takes place. The authors of “Public Stem Cell Banks: Considerations of Justice in Stem Cell Research” take a novel approach to the issue of justice in stem cell line access. What is particularly salient in the article is the authors’ concern to establish the kind of stem cell banks that might ameliorate the problem of “unequal biological access.” As the authors show, this is a justice concern of high order: unless we create stem cell lines that *deliberately* mirror the biological diversity of the American population, the consequence will be a public bank that, intentionally or not, is likely to deprive minority ethnic and ancestral groups of the benefits of developing stem cell therapies.

Such a system would, in the authors’ view, perpetuate a history of injustice to American ethnic minorities. In addition to the legacy of Tuskegee in medical research, the Human Genome Diversity Project had a questionable early history of DNA-typing indigenous populations in the Global South to benefit the Global North. In this context, the authors’ proposal merits careful attention.

The authors consider three strategies for arriving at just access to stem cell therapies in American society: (1) a “coverage maximizing” strategy, a utilitarian calculus that “allows the greatest percentage of the population to find a matching line in the bank” by storing the most common haplotypes; (2) an “equal chances” strategy, which would give “all who it is feasible to include an equal chance at having their HLA in the bank” through a randomized process of inclusion; and (3) an “ancestral-ethnic representation” strategy, which would select stem cell lines containing common alleles within major population groups. The ancestral-ethnic strategy would make a stem cell bank “useful to the same percentage of patients from each ethnic category.” In contrast, the coverage maximizing strategy, by seeking to benefit the largest number of people, would favor Caucasians. The equal chances strategy would use a “Rawlsian” randomized method of selecting HLA types, and although the procedure itself might be fair, the fairness of its outcome cannot be predicted.

In a sense, the ancestral-ethnic representation strategy, which the authors advocate, seems to me to be a kind of affirmative action for stem cell lines and HLA-matching, although it would aim not so much to redress past imbalances as to avoid exacerbating them. I am sympathetic to affirmative action strategies for rectifying a history of racial imbalance in public access, and I find the approach appealing.

The authors argue, citing allocation methods for organs and ICU units, that a lottery is not the only fair means of distributing scarce health care resources to which no one is “antecedently entitled.” But the organ donation system is of limited help, and I am not persuaded that it should be pursued as an analogy for distribution and access to public stem cell banks, given the problems that beset it. In a discussion of how to obtain gametes for the creation of stem cell lines, the authors return to the organ donation analogy and advocate that gametes be donated, not *bought*—in contrast to the assisted reproduction industry, where market forces determine payments for what are wrongly called “donations.” But probably the organ donation model is neither transferable nor desirable for a public stem cell bank, and a more realistic approach might rely on regulated capitation payments.¹

Nor do I think the issue of antecedent entitlement can be set aside, and indeed the authors’ own argument for the ancestral-ethnic model seems to lend itself to a claim for antecedent entitlement by minority groups on the basis of past injustice. The appeal of feminist bioethics includes a similar sort of demand—that the needs and concerns of historically oppressed groups perhaps be given a privileged position in terms of health care access and allocation. Susan Sherwin has insisted that medical research should be evaluated “in terms of its connection with existing patterns of oppression and domination in society.”² Faden and colleagues are to be commended for giving us a novel rationale for preserving the biological diversity of stem cell lines, while meeting some of the demands of justice that a feminist analysis entails.

1. S. Holland, “Contested Commodities at Both Ends of Life: Buying and Selling Gametes, Embryos, and Body Tissues,” *Kennedy Institute of Ethics Journal* 2, no. 3 (2001): 263-84.

2. S. Sherwin, *No Longer Patient: Feminist Ethics and Health Care* (Philadelphia: Temple University Press), 175.

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