

BOOK REVIEWS

The AIDS Engagement

Impure Science. AIDS, Activism, and the Politics of Knowledge. STEVEN EPSTEIN. University of California Press, Berkeley, 1996. xiv, 466 pp. \$29.95 or £25. ISBN 0-520-20233-3. Medicine and Society, 7.

This is a moment of heightened therapeutic enthusiasm regarding AIDS. From the depths of despair in the wake of the Concorde trial, which challenged the assumption that early treatment with AZT could extend the lives of those with HIV infection, we have moved to a kind of (premature) triumphalism marked by claims about the life-extending, life-enhancing benefits of combination therapies including the protease inhibitors. At the recent International AIDS Meeting in Vancouver a plenary session could be the occasion for a respected scientist to raise the prospect of eliminating HIV from those already infected.

It is in this context that I came to read Steven Epstein's remarkable book *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Here is a study marked by scrupulous attention to detail that is at the same time almost breathtaking in its scope and probing in its analysis. It is at once a fine contemporary history of science, a sociology of knowledge, and an account of the emergence and fate of a social movement driven by rage and passion. At a moment when all eyes are on the future, fixed on the question of whether the new therapeutic strategies will—at least for those who live in countries where they are affordable—have more than limited efficacy, it is instructive to look back on recent history as a way of understanding how we came to this juncture.

In the epidemic's first decade there were a number of volumes that detailed the deep controversy centering on the tensions between the claims of public health and those of individual rights. In those struggles AIDS activists forced a reconsideration of the authoritarian premise of the public health tradition and were central to the shaping of a broad voluntarist consensus that marked off HIV from other infectious threats. No history of the emergence of "HIV exceptionalism" could be written that did not attend to the politics of public health.

But if the notion that public health must always entail political choices still provokes controversy, how much more so does the

idea that the conduct of science is socially embedded, that progress itself may entail political conflict. It is to that terrain of battle that Epstein draws us in his account of the dispute over whether HIV is the cause of AIDS and the struggle on the part of AIDS activists to reshape the process of research into and trials and regulatory approval of therapeutic agents that might meet the clinical needs of people with AIDS.



Vancouver AIDS conference, July 1996.

In the introduction to *Impure Science*, Epstein establishes his own self-imposed challenge:

There is no romantic tale of resistance that privileges the "purity" of knowledge-seeking from below; rather I argue that the cultures of experts significantly encroach upon and transform those of the lay people who would engage with them. Nor am I interested in cheerleading, despite my strong sympathies for AIDS activism. What makes the story of this engagement with biomedical expertise interesting and important are the ironies and tensions embedded in the process of forging novel scientific, political, and moral identities. This is a complicated history in which no party had all the answers. All players have revised their claims and shifted their positions over time; all have had to wrestle with the unintended consequences of their own actions.

In a world in which participants in controversy tend to veer off into hyperbole Epstein's posture comes as a welcome antidote.

In his chronicle of the controversy over the etiology of AIDS, Epstein takes pains not to write the history from the "victor's" perspective. It would have been too easy from the vantage of 1996—given the new-found evidence regarding the momentous biological struggle that occurs in those who become infected with HIV—to write derisively about the claims of those who have argued that

HIV is not the cause of AIDS. It would have been too simple to characterize Peter Duesberg as a brilliant scientist who had become the tragic captive of an *idée fixe*. Because Epstein has resisted such seductions he is able to lay bare the intricate web of scientific argument, empirical data, and politics that has framed this controversy.

When Epstein turns to the struggle on the part of AIDS activists to speed the progress of clinical work, he becomes far more engaged. But he does so with self-discipline and the kind of attention to detail that permits him to trace a narrative account that is both moving and provocative. Especially interesting are his efforts to reconstruct the evolution of activist efforts first to prod the Food and Drug Administration into approving drugs more rapidly (the strategy of moving "drugs into bodies"), second to reshape conduct of clinical trials, and finally, in desperation, to foster new efforts at basic scientific research.

The process involved the mobilization of bodies in mass demonstrations, reliance on the tactics of disruption, and threats of intimidation common to other social struggles. But, in addition, lay activists, in a remarkable act of self-education, transformed themselves into experts able to argue with their scientific interlocutors at levels of sophistication that no one could have imagined. It is in describing this transformation that Epstein provides us with some of the most interesting analysis of what happens to outsiders as they become experts, a transformation crucial to the struggle for legitimacy yet threatening to the linkage of the AIDS activists with the mass base from which they emerged.

To those who adhere to the view that political intrusions can only distort the course of scientific work, Epstein's description of how AIDS activists fostered and helped to shape the progress of AIDS work will be intellectually jarring. To be sure, there were false starts and mistakes. To be sure, the politics of change were sometimes crude, sometimes cruel. But there were cruelties associated with the status quo as well. To some the intrusions upon science had the whiff of storm trooper fascism or of Stalinist Lysenkoism. But in the end, as Epstein makes clear, AIDS activists had too much to gain from "good science" to act in ways that would subvert the search for effective therapies.

What makes *Impure Science* so good to read is that Epstein provides an account that has a clarity and narrative style that stands in contrast to the murky formulations by students of science that he sometimes feels compelled to cite. What makes it important to read is that it is fiercely honest.

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