

INTRODUCTION

To the Moon

Before we start designing ways to get to the moon, can we just make sure everybody on my block can actually get to work?

—*Patricia Berne, scholar-activist*¹

The fear of imagination in politics comes from the fear of illusion. It is like refusing to use a tool at all because it can be misused.

—*Richard Sennett, Authority*²

ON FEBRUARY 16, 2007, I sat in a San Francisco Sheraton meeting room waiting for then California governor Arnold Schwarzenegger to appear. The governing board of California's new stem cell agency had scheduled a press conference for the governor to announce his approval of a \$150 million loan to fund the first round of scientific grants to stem cell researchers. This move by the governor was politically significant, according to Donna Gerardi Riordan, director of programs at the California Council on Science and Technology, "because it occurred one day after President Bush vetoed bipartisan legislation that would have relaxed federal restrictions on stem cell research."³ The loan was necessary after \$3 billion in state bonds that should have been available to fund the agency's work were held up by two lawsuits arguing on pro-life or consumer rights grounds against the California Stem Cell Research and Cures Initiative.

Having attended a number of the stem cell agency's public meetings, I was routinely mistaken for a journalist as I hurriedly typed my field notes; so on this occasion I was ushered into the front row of the press conference, several feet away from the podium. By the time the governor arrived, leaning on a cane on account of a skiing accident, the room

was abuzz with anticipation. He congenially shook hands with about a dozen of the board members and patient advocates standing at attention behind the podium, his limp in sync, as it were, with the impairments of those advocates placed front and center in wheelchairs, wearing their “Stem Cell Action Network” buttons. As the buzz turned to a hum and the hum gave way to absolute quiet, the governor began:

These initial grants today are very important because you all know we cannot afford to wait when it comes to advancing life-saving science. So today is a day of great hope. We have hope for promise of incredible advances in medicine. Hope for the eventual end of suffering from diseases like Alzheimer’s, Parkinson’s, cancer, and MS and hope for the people who love someone with one of those terrible diseases. . . . I know a lot of people in California and around the world that have diseases like that and can be helped with this important research. This is why we are not waiting for anyone to do it for us. We are creating the action right here in California [audience applause].

I also want to show my deepest gratitude to the scientists and to the doctors who are receiving this money to find new therapies and new cures. I just want them to know that I am 100 percent behind you and the people of California are 100 percent behind you. We think the world of them. They are opening up possibilities that only a few years ago, we would have only imagined. So they are our newest action heroes [audience laughter], and I am looking forward to what they can achieve.⁴

Strategically distancing himself from an unpopular U.S. president who had just restricted the work of stem cell researchers, the governor effectively invoked the hope and heroics that have animated this new field since the isolation of human embryonic stem cells in 1998. But whereas the governor’s comments focused on the heroics of scientists, it was the actions of the advocates, policy entrepreneurs, lawyers, and journalists in the room that in fact had enabled passage of the stem cell initiative—and the scientists were beholden in many ways to these various

constituencies and their sometimes competing agendas. This shifting relationship between science and society is what *People's Science* sets out to explore, revealing those struggles, both manifest and veiled, that animate science shaped by public demands.

The limits of the old trickle-down relationship between science and society, in which the public was expected to patiently wait for the fruits of science to reach it,⁵ first grew apparent in the wake of the 1945 atomic bomb tests. Since then, the controversy over genetically modified organisms that started in the 1970s and continues today; the revelations of the Tuskegee syphilis trials; and reports of numerous medical abuses against women, racial and ethnic minorities, people with disabilities, indigenous populations,⁶ and prisoners,⁷ together reveal the underside of scientific innovation. Greater awareness that these are not fringe events carried out by hacks and mad scientists but often take place in mainstream institutions, frequently at the direction of the most prominent members of their fields, has fueled a growing movement against allowing researchers to govern themselves, in isolation from wider social norms.

But what some consider the “contamination” of pure science is not only a bottom-up process of citizens demanding more input and regulation.⁸ The commercialization of scientific research has also increased exponentially. The federal Bayh-Dole Act was passed in 1980 to encourage the more efficient commercialization of research, thereby incentivizing the pursuit of profit on the part of researchers. The rapid growth of patent licenses and the widespread development of technology transfer offices at public institutions, having a mandate to identify research ideas that could be developed into commercial products, raise new concerns about the conflicts of interest that frequently inform scientific investigation. In a landmark case that some call the “Brown v. Board of Education for genetic science,”⁹ the U.S. Court of Appeals for the Federal Circuit “affirmed the right of Myriad Genetics to patent two genes linked to breast cancer [BRCA-1 and -2] overturning a lower court ruling that threatened a key element of the biotech business.”¹⁰ Critics of gene patenting say it creates a monopoly that impedes research “that could lead to better diagnostic treatments” and prevents competition,

which ultimately forces consumers to pay more and limits women's treatment options. "Tests that cost \$300 end up costing \$3,000 because of the patent monopoly that the company has," said Lori Andrews, a law professor at Chicago-Kent College of Law.¹¹ By contrast many in the biotech industry are relieved by the ruling: Goldman Sachs analyst Isaac Ro said the Myriad ruling lifts a "near-term threat to investors," even as he and others expect the legal fight to continue.¹² The life sciences and the burgeoning biotech industry are especially vulnerable to conflicts between commercial, medical, and broader social interests, as the application of commercial logic to (and commodification of) the human body leads us full circle to the dangerous medical practices of World War II—and even prior to that, to American chattel slavery. Together, these ethical and commercial concerns have laid to rest the figure of the disinterested and autonomous scientist traversing what Vannevar Bush, in a Report to the President, once called the "endless frontier" of knowledge.¹³

But while some observers worry that the cloistered and disinterested ideal has been replaced by self-interested, profit-seeking scientist-entrepreneurs,¹⁴ evidence suggests that many scientists are taking a longer view. A long list of eminent scientists spoke up in support of the American Civil Liberties Union case against the Myriad patents. In less litigious contexts, some are going so far as to leverage the far-reaching implications of their work to resonate with a broad public mandate of health access and democratic inclusion.¹⁵ They are supplanting the trickle-down ideal with a participatory ethos, in name if not in practice, in which they engage with nonscientist stakeholders at ever earlier stages of the research and development process. Often this engagement is geared toward supportive patient advocates who provide the moral imperative for rapid scientific development; but sometimes other constituencies manage to get the attention of the scientific establishment.

Indeed, the giving or withholding of public approval has grown more direct: in over a dozen U.S. states, initiatives to fund or ban stem cell research have come to a popular vote. California's Stem Cell Research and Cures Initiative was one such effort, in which scientists,

policy entrepreneurs, and patient advocates worked together to achieve unprecedented investment in and insulation for the besieged new field. On November 2, 2004, Proposition 71 successfully passed, following a massive “pro-cures” campaign that linked investment in the new science with the alleviation of suffering from over eighty diseases. It authorized the sale of state bonds in the amount of three billion dollars over ten years, to be managed by a new stem cell agency (the California Institute for Regenerative Medicine, or CIRM), which would be protected by an amendment to the state constitution that created a “right to research.” The text of the initiative also stipulated that the new agency was to be governed by an Independent Citizens’ Oversight Committee (ICOC), the composition of which has proven an ongoing locus of struggle over the legitimate parameters of public inclusion and representation.¹⁶

Compared with the old, cloistered model of science, the initiative and its governing structure appear radically inclusive: approval is by the voters, funding by taxpayers, and governance by representatives of the public. Yet it still does not fully address the concerns and expectations characteristic of the participatory trend in science development. Many of the board’s critics point to the economic and institutional conflicts of interest that may cloud members’ ability to implement Prop. 71. (One such conflict forced the resignation of a board member who held stock options in a company that had applied for a grant from the stem cell agency.) Beyond this, however, I suggest that a *lack* of constructive conflict over the priorities and governance of science poses an even more fundamental challenge to a truly participatory initiative such as this. The lack of public accountability to, and inclusion of socially subordinate collectives is, in my estimation, more politically worrisome and sociologically interesting than is the stain of stock options. Without this deeper accountability, proponents of a “right to research” are sacrificing social equity at the altar of scientific expedience.

The lack of robust deliberation about how scientific initiatives can and should reflect a wider array of social concerns is due in part to the systemic exclusion of those who could articulate concerns about state investment in stem cell research from working-class, feminist, disability,

or racial justice points of view. But these omissions also stem from a fundamental ambiguity about who “the people” of participatory science initiatives are and should be. In focusing on how “the people” of a people’s science are constructed and contested, I offer a critical understanding of the processes of inclusion and exclusion that typically remain hidden in depictions of “the stem cell debate.”

These struggles over the credible parameters of involving people’s bodies *and* interests in stem cell research are fundamentally different from nonscientific political struggles, because the question of what the state owes particular groups is intimately connected to biological definitions of *what constitutes a group* in the first place. The coemergence of novel life sciences and new rights claims that “redefine the obligations of the state in relation to lives in its care” is what Harvard professor Sheila Jasanoff terms *bioconstitutionalism*.^{17, 18} We see glimpses of bioconstitutionalism in the now codified “right to research” brought about by the passage of Prop. 71. But we also find it in the pro-cures assertion that it is a right of families to pursue the best course of treatment for their loved ones despite the ethical toes such treatment steps on. This relationship between a “right to research” in a laboratory and sociopolitical rights in the political arena does not pertain simply to the realm of official policy and legislative enactment. Rather, we find it in *bioconstitutional moments*, where struggles over who *we* are, what we are owed, and what we are responsible for, as both objects and subjects of scientific initiatives, are taking place all around us. In California and a growing number of jurisdictions, representatives of various constituencies are attempting to codify answers to these questions.¹⁹ In an even greater number of arenas, people have yet to formalize answers but are tinkering with and sometimes brawling over the role and interests of the public in conducting controversial science.²⁰

A political sociology of science requires that we examine not only courts, legislative sessions, board meetings, and ballot boxes but also funding agencies, hospital clinics, and other, more mundane sites where the meaning of life and the entitlements owed to the living are negotiated and contested. In this way, the seeming exceptionalism of Califor-

nia gives way to an expanded social terrain with a common propensity to struggle over boundaries of inclusion. It is upon such fractured ground, and not upon any firm authority and hegemony on the part of science *or* overwhelming trust or consent on the part of society, that public engagement with science is taking place. People do not simply “hold” stakes but actively construct and calibrate the risks of aligning their interests with scientific initiatives, forming the supple social infrastructure of stem cell research and related life sciences—what one racial justice advocate working on organizing a coalition to demand greater inclusion for minority health interests in the California stem cell initiative called a “house of cards.”²¹

In contrast to the polarizing frames of Right-Left politics, so much of the actual work to advance or oppose scientific research is carried out via politically promiscuous bedfellows. We find a pro-choice alliance teaming up with the Catholic Church to object to the use of oocytes for research; a sickle cell disease organization signing on to a stem cell campaign only to be formally excluded from the initiative’s implementation; and conservative activists such as Mel Gibson speaking out against state investment in “unethical experimentation” to a predominantly working-class African American community in Watts, Los Angeles, whose local health clinic had closed on account of budget cuts. Such novel alliances and collaborations are indicative of the way in which a controversial scientific field does not simply fall along old sociopolitical boundaries but redraws them in unpredictable ways.²²

Consider one such foray into this shaky social terrain. In the fall of 2006, Dr. Zach Hall, former National Institutes of Health director and president of the new California stem cell agency, found himself in front of an unlikely audience. Nearly two years after the historic passage of Proposition 71, Hall was invited by members of the Oakland-based Black Wall Street Merchants Association and the Black Board of Trade and Commerce to participate in a “two-way dialogue” about the significance of stem cell research for African Americans. The ensuing town hall-like forum, with over two hundred physicians, lawyers, clergy, heads of social service agencies, and community college and public

school administrators in attendance, was eventually televised on a local station. Hall fielded questions about whether diseases affecting the African American community would be prioritized by stem cell researchers; how small black-owned firms could compete against more established companies for grants; and strategies for African American students and scientists to be drawn into the stem cell career pipeline.

Even as forum attendees expressed a strong interest in the wider social and economic impacts of stem cell research, Hall attempted to gently resist these larger public considerations. Presentation slides and luncheon plates in place, Hall explained that the official text of the stem cell proposition did not in fact entail the social inclusion priorities that attendees raised. He also hinted that it was not realistic for the small staff of fifty people at the new stem cell agency to prioritize early-stage research based primarily on its impact on a particular population or tackle such deeply entrenched problems as the unequal availability of science education. Acknowledging the importance of such endeavors without accepting responsibility for advancing them, he carefully tried to hold together the fragile bond symbolized by Prop. 71. He did so by staying as close to the science as possible and then astutely drawing participants' attention to the problematic politicization of science by the opponents of stem cell research. After explaining the basics of the field, Hall emphasized the importance of a diverse pool of tissue donors to ensure the future applicability of stem cell treatments to African Americans, noting that

[i]f stem cells are to be useful for all members of our population, we want stem cells that reflect in their genetic characteristics all the diversity found in the human population, and the problem with in vitro fertilization clinics, as somebody said, it's a very limited population. They have to be rich, white, and infertile. And we need more stem cell lines than that. We need stem cell lines of all sorts, of all sorts of people.²³

In effect, Hall resisted the role of populist scientist being thrust upon him even as he carved out a much more biologically circumscribed understanding of how scientists could ensure a science "for the people." He

proffered a kind of inclusion based on the presumed genetic diversity of different races, offered as evidence of the agency's forward-thinking agenda, even as he relied on an older notion of biologically based racial differences as the primary basis on which the initiative was prepared to consider the inclusion of African Americans.

Remaining noncommittal with respect to the various visions of social inclusion offered by the attendees, ideas that he promised "to take back to the board," Hall instead carefully weighed in on the major fault line then dominating the stem cell terrain, namely the moral status of embryos. He explained that one of the groups suing the new agency called themselves the National Association for the Advancement of Preborn Children (NAAPC), inverting the last two letters of the well-known civil rights organization, the National Association for the Advancement of Colored People (NAACP). Audience members let out a knowing groan at this appropriation, whereupon Hall noted that the NAAPC's lawsuit was on behalf of an unborn child named "Jane Scott Doe"—the plaintiff's middle name evoking that of Dred Scott, the African American slave who unsuccessfully sued for his freedom in 1857.²⁴

Betting that his audience would find the conflation of American chattel slavery with the use of embryos in research disingenuous if not offensive, Hall successfully drew attention away from his noncommittal stance on the social inclusion issues raised at the Oakland forum, and toward the machinations of the NAAPC. In focusing on the problematic politicization of science on the part of the agency's adversaries, Hall implicitly cautioned his audience that such political contamination would slow the development of cures. In so doing, he never had to say that the participants' demands for a broader social commitment posed a similar threat.

When I sat down with the president of the Black Wall Street Merchants Association, Eddie Dillard, to discuss the accountability of the fledgling stem cell agency, he was adamant that "if we're gonna pay, we need to play!" even as he hedged about what "playing" in this speculative terrain would actually look like. He and others on the front lines of advocating inclusion for racial and ethnic minority, feminist, and

disability concerns in publicly sponsored science initiatives seek to challenge the invisible interests of the amorphous “public” to which Proposition 71 was pitched, though they do not necessarily have a full-blown alternative to propose. Even so, they appear to understand that accountability cannot be achieved in an afternoon dialogue or a onetime Q&A session but only via an ongoing and fully institutionalized means of ensuring that in the case of stem cell research, social goals, and not only biomedical goals, are addressed. In the words of one of the more outspoken racial justice health activists, Joseph Tayag, ethnoracial minorities “need to be *at* the table, not just *on* the table” of stem cell research.²⁵

This Oakland forum, in which participants sought to actively construct, not simply “hold,” specific stakes in stem cell research, exemplifies the new contract between science and society that is being negotiated in California and elsewhere. Confronted with the complexity of implementing an initiative like Proposition 71, its architects are faced with the fragility of their pact with the public. Amid the great diversity of the electorate, whose interests should take precedence? Through what channels should they be heard? By what standards should science be held responsible? In short, now that the science “for the people” rhetoric had achieved its purpose, winning onetime approval at the ballot box, how would consent be maintained? How would accountability be enacted and, in time, contested?

These and more questions not only animated the Oakland stem cell forum but are part of a larger process of political experimentation in which the parameters of social inclusion in science are being redrawn. The issues raised and dodged at the Oakland luncheon, in terms of which scientists and various publics typically negotiate the broader stakes of scientific investment, have figured in public debate in over a dozen states that have used electoral and legislative processes to fund or ban stem cell science. At the same time, the United States lags far behind the participatory mechanisms well underway outside of the country: “science shops,” in which researchers collaborate with citizens; “science courts,” in which laypeople pass judgment on scientific controversies; “citizen boards” to assess technological risks.²⁶ In all these ef-

forts, scientific norms still tend to outweigh wider social norms in terms of quality control and with respect to measuring success. Examining what gives these hybrid political-scientific experiments legitimacy and staying power—whether the authority of science, populist exuberance, or as I argue, the strategic fabrication and mobilization of a particular kind of consenting public—is one of the tasks set forth in this book.

To the Moon?

In 1998, University of Wisconsin developmental biologist James Thomson announced that his lab had managed to isolate and culture human embryonic stem cells from the inner lining of a human embryo, a feat achieved until then only in animals.²⁷ Soon after, frenzy ensued. As one commentator predicted, “the stage was set for a raging battle in which scientists, politicians, religious leaders, doctors, and patients would find themselves unwilling soldiers.”²⁸ For many opponents of the technique, the potential benefits of such research were offset by the ethics of sacrificing what they regarded as a potential person in the process. For many who believe that human life begins at conception, the cost of using this technique was too high. Supporters of stem cell research, by contrast, weighed the possibility of relieving human suffering against such considerations. For them, the status of an eight-day-old embryo (blastocyst) was qualitatively less certain than that of living, breathing human beings who could benefit from regenerative medicine.

The issue of potentiality—potential humans and potential cures—pulls at both ends of the stem cell debate, impacting those not only in the research laboratory but in the political arena as well. The divergent hopes and fears surrounding the tools we use for both scientific and political experiments remind us how “the politics of biotechnology serves as a theater for observing democratic politics in motion.”²⁹ Owing in large part to the technical advances of Thomson and colleagues, stem cell research has grown to be a wedge issue that both the political Right and Left use to cast the other side as enemies of life. Depending on how exactly one frames Thomson’s achievement, the new field reflects mankind’s ingenuity—or its fall from grace.