PREFACE

As a social scientist interested in learning how science and technology can serve as a window onto broader questions of health, equity, and justice, I have often felt pressured to bracket my personal experiences so as not to "taint" my analytic gaze. This, despite the fact that those we might call *non*–social scientists, who practice the "hard" disciplines, are socialized within particular cultural milieus and known to bring their personal biographies into the lab.[1] I inevitably still struggle to study the social world while caring deeply about what kind of world we bring into being, and so I have worked to sharpen an objectivity grounded in self-reflection, one by which I take stock of my experiences, assumptions, and commitments so that I can produce a more complete and contextualized representation of my research subject.

As life would have it, a week before the final revisions of this manuscript were due, my father was rushed to the hospital with strokelike symptoms. Having already undertaken the massive task of learning to walk and work again after his left side was paralyzed due to a stroke three years ago, *here he was again*: in a small hospital room at Cedars-Sinai, where neurologists were trying to figure out an effective course of treatment. This time around there was one crucial difference. After his first stroke, my dad's employer-based health insurance covered the multiple tests, treatment, and physical therapy that allowed for his slow recovery. But this time, working in a new and precarious line of work, he was uninsured. So the longer, more substantial, and perhaps more effective his treatment turns out to be, the bigger and more burdensome the bill that awaits him when he eventually checks out of the hospital.

There is little doubt that this and similar firsthand experiences, where I have been confronted by the coexistence of abundance and scarcity, form the invisible dark matter that holds these pages together. Social principles in this way are the corollary of scientific theories—by putting them aside we are choosing not to see important features of how reality takes shape. Like those who investigate dark matter itself, our evolving understanding is not an inevitable outcome of simply using particular tools.[2] Instead, our *ideas* about the relationship between different parts of the universe, our refined assumptions, make it possible to detect forces that were completely invisible before. The more we are attentive to our theories and principles, the better our research; not only is our capacity for producing data enhanced but hopefully so is our ability to revise our assumptions when confronted with the unexpected. A social principle in this way can and should share the flexibility of a theorem.

This brings us to one of the core themes of this book: in a society of haves and have-nots, the biomedical ingenuity that can bring people back from near death has a *double edge*—one side excising brain embolisms from blood vessels where they do not belong, and the other side deepening the fault lines through which our current social order distributes suffering and premature death in radically uneven ways. As Jo Phelan and Bruce Link put it, "[w]hen we develop the ability to control disease and death, the benefits of this new-found ability are distributed according to resources of knowledge, money, power, prestige, and beneficial social connections."[3] But does this mean biomedical ingenuity must *necessarily* deepen inequalities? Before undertaking this study, I assumed so, in part because I experienced science and medicine primarily as an outsider and was not aware of the openings through which innovation and equity could be mutually constructed.

My experiences as an "outsider within" tell me we don't have to put scientific innovation on hold for more equitable social relations to first take shape.[4] Instead, we are in dire need of bolder visions of innovation that are seeded with a commitment to invigorate more equitable social relations *alongside* the pursuit of regenerative medicine and other fields. This necessitates that conditions we already know to foster health and

well-being are not taken for granted in the process. Drawing attention to the "shadow realities"[5] of those who do not have access to affordable healthcare will, for example, make it apparent that a more varied people must participate in the governance of science, technology, and medicine, fully contributing to the decisions that impact their lives and, even more fundamentally, their life chances.

As an African American woman of mixed ethnic heritage and someone who specializes in qualitative research methods that require a fair amount of interpretation, my precarious location in the academy has heightened my attention to this question of how experiences shape knowledge production. I have walked a fine line in the pages to come, seeking to represent the social and political struggles over new biotechnologies with *commitment* to the principles of equity and justice I hold dear, and with *fairness* to my research subjects. Some readers may come to question my evenhandedness, wishing I had infused less assessment and interpretation of the stakes of these struggles into this work, while others will wonder why I did not come down harder on one side or another. To both I acknowledge, the line I walk is more like San Francisco's Lombard Street. Crisscrossing the landscape of scientific empiricism and cultural meaning, my aim is less to strike a perfect balance *or* arrive at a final destination than to introduce those I have met along the way to others whose social worlds they may have ignored, dismissed, or misunderstood.