

PREFACE

On January 11, 2008, I lost my good friend Chet Meeks to colon cancer. Chet was, without a doubt, one of the smartest, most talented scholars I've had the good fortune to know. I learned a great deal from him over the years. Chet was just thirty-two when his cancer was first diagnosed; he died two years later.

Chet did not lead an unhealthy lifestyle. He was not genetically predisposed to colon cancer. No one in his family had been diagnosed with colon cancer. The etiology of Chet's cancer was, and will remain, a mystery, although he often wondered about the years he spent living near the Hudson River, polluted with polychlorinated biphenyls (PCBs), when he was pursuing his PhD in sociology.

Determining ultimate causes is not, understandably, high on the list of one's concerns when diagnosed with cancer. Chet's goal was treating the cancer and curing it despite considerably bad odds. For the cancer patient, little emotional or intellectual space exists for theorizing one's disease in the midst of learning about the medical array of tests, treatments, and "cures."

Nevertheless, I know that Chet was, on some level, encouraged by the work I had been doing on genomics, epidemiology, and the politics of cancer, keeping conceptual and critical questions on the table, holding onto the necessity of theory in the midst of crisis—of real, in-your-face, material exigency. He was, after all, a social theorist. Although theory can be abstract, it is also an indispensable tool for making sense of the varied and often contradictory details of individual and collective embodied experience and everyday life. As Paula Treichler reminds us, "theory is not the creature disdained by . . . anti-intellectual traditions, including U.S. medicine, for whom *theory* is defined as that which is devoid of relevance

for 'practice' and real-life experience. At the end of the day, *theory* is another word for *intelligence*, that is, for a thoughtful and engaged dialectic between the brain, the body, and the world that the brain and the body inhabit."¹

Theorizing disease in this way—as engaged dialectic between brain, body, and world—is to ask how it is at once an experience of the corporeal body and also a historically variable concept that emerges from how we think about, discuss, and name disease, in both institutional and cultural contexts. This explains, for instance, how it is that the bodily experience of disease is largely determined by what its counterpart—normality or health—means. Moreover, the process of becoming a patient is invariably influenced by accepted understandings of race, gender, sexuality, and class status. Together, these bodily attributes and conceptual frameworks make some interventions possible, but not others, and these interventions in some cases can be matters of life and death. Theorizing disease and the body thus ultimately serves the pragmatic needs of medicine—including genetic medicine, which, we hope, will provide more humane cancer treatments that target somatic cancer cells—to alleviate suffering and tend to bodies existing at the interstices of health and illness, however contingent and contextually bound those concepts and states of being might be.

This book also explores what happens when we think of biomedical discourse as political. How, for example, does disease index the kinds of environments and social relations that we embody? Because bodily attributes like gender and race are laden with political and social significance, how is the process of becoming a patient simultaneously a biomedical phenomenon and a sociocultural and political one? And if the body is the site for the material convergence of social relations, how might it also be the site for social and cultural resistance, albeit without enacting the problematic logics of biomedicalization? Although epidemiology provides important and useful models for understanding the social dimensions of disease, it nevertheless is limited in what it can tell us about the world the body lives in. In the final analysis, epidemiology depends on the body as the site for action and not the political, economic, and social structures responsible for the collective experience of disease.

Heredity—a particular way of thinking about bodies, risk, and, by extension, the social and economic order—is fundamentally at odds with the notion that disease is the corporeal effect of embodied social relations. On the one hand, heredity, or the idea that one is born with various susceptibilities, hyperindividualizes and privatizes risk and disease. Genomic

medicine predicts a future of what is called personalized medicine, wherein a patient's genome becomes the site of diagnosis and treatment of risk. On the other hand, hereditarian thinking imagines patients racially, which means that personalized medicine has the potential to become yet another privilege of white patients, for whom race does not enter into diagnosis and treatment practices.

Despite the paradox whereby genomics simultaneously reifies both individuals and populations, its immanent hereditarianism nevertheless effects a crucial displacement in both cases: disease is evidence of inherited defects, not embodied life. Genomics is, then, more than a disease paradigm—it is a political worldview that has been both a constant in US history and a particular way of performing ideological work during discrete moments in that history. Indeed, my interest in genomics began long ago with the question, what makes the genomic model of disease distinct from other models? The answer to that question emerged largely through a particular reading of eugenics. During a regrettable period of history in which a vicious racism and nativism intersected, however tangentially, with the newly discovered theory of heredity, eugenics justified—in the minds of reactionaries and progressives alike—the figurative and literal criminalization of blacks, women, immigrants, and poor people. Why, I ask in this book, has heredity remained uniquely suited to the task of constructing biopolitical discourse during crucial and sometimes painful phases of industrial capitalism and emerging social movements and discourses of resistance?

To understand why it matters that Chet was stricken with an aggressive cancer at such a young age, we must think beyond his individual body and the treatments it required. We must think of his experience through the framework of collectivity: of his body located in space and time with others, living in environments and social relations not of their own making but resulting from deeply politicized and self-interested corporate, governmental, and institutional practices. To answer the questions I pose requires the humanist's eye, located a safe and critical distance from the disciplinary norms of genomics, medicine, and public health.

In the spirit of scholarly inquiry, and in memory of Chet's unrivaled intellect and sense of humor, I present the following study.