PREFACE

THIS IS A HISTORY OF PROMISES. Scientists, physicians, and reporters tell us that DNA science will enable us to live longer and to know when we will die. We will predict the diseases we will get and forestall them with drugs or lifestyle changes. Medicine will become "personalized": our doctor will know us literally outside and in, and so will be able to tailor medical care to our individual needs. We will know whether we are idiosyncratically sensitive or insensitive to a drug and whether that drug will be beneficial, inert, or toxic to us. Medicine will become a predictive, preventive science. We will simultaneously receive better care and have more control over and autonomy in our healthcare decisions. Ultimately, we will be able to engineer ourselves to eliminate disease, disability, and weakness, and we will guide our own evolution.

Although these promises have a glossy contemporary shine, they are recycled. Medicine has been going genetic—and genetics going medical—for more than a century. The claims and promises of genetic medicine predate DNA, the mapping of human genes to chromosomes, even genes themselves. It is not my task to evaluate whether these promises are realistic or can be kept. My goal is to uncover their origins, to illuminate their context, and to explain their meaning.

Medical genetics—or, more broadly, medical *heredity*—has always stemmed from two impulses: toward the relief of suffering and toward human improvement. The first is compassionate, medical, individual; to

oppose it is misanthropic. The second is more complex. In the abstract, human improvement may be a laudatory goal, but hereditary human improvement denotes changing the nature of the population. It carries suggestions of human engineering, and of the objectification of the engineered. It is fashionable but disingenuous these days to assert that the relief of individual suffering is noble and population improvement insidious. Both are in fact both. Relief of suffering is humanitarian but raises issues of paternalism and autonomy. Deliberate efforts at human improvement may have the population's best interests at heart, but willy-nilly they involve social control.

The history of medical genetics is usually related as part of the larger history of human genetics. Over the years, a master narrative of human genetics has crystallized, in which the study of human heredity evolves from a focus on human improvement to one on relief of suffering. Medical genetics emerges out of this "medical turn" in human genetics, which occurred at mid-twentieth century, in the years following the Second World War. This narrative allows one to acknowledge the distasteful origins of human genetics in eugenics—often defined in the words of the Progressive-era geneticist Charles Davenport as "the science of human improvement through better breeding"—while distancing oneself from it. The eugenic origins of human genetics are sequestered in the past, separated from modern medical human genetics by the historical firewall of World War II. Historians of eugenics have nuanced and deepened this narrative of a medical turn in human genetics, but they have largely retained its architecture. Years of scholarship have transformed the firewall into a membrane, multiply pierced with postwar eugenic practices and affiliations. Such work adds needed context, reflectiveness, and conscience to the often overamplified discussions of the promise of scientific medicine. Yet even with all this welcome texture, eugenics still tends to be construed as a "bad idea," even a pseudoscience, that has an insidious tendency to leak back into legitimate attempts to understand the hereditary basis of health and temperament. Eugenics is treated as exceptional, a scientific/social/political movement bound in time, an unfortunate phase in the history of human genetics. There remains in much of the scholarly discussion a sense that eugenics is a contaminant of good, honest biomedicine.

In contrast, in this book I treat human improvement and the relief of suffering as the two goals of all eugenics—and all medical genetics. Where previous accounts have documented the medical turn in human genetics, I trace, rather, a thin medical thread in studies of human heredity. It reaches back to the beginning of the twentieth century, gradually thickens, and comes to dominate scientific approaches to human heredity. Even at the beginning of the century, advocates of hereditary health made promises identical to those we hear today: genetics would make us healthier, longer-lived, smarter, happier—better. These goals were eugenic goals. I am interested less in the eugenics movement, which is historically situated in the Progressive era and interwar period, than in the eugenic impulse, which is timeless. It is the urge toward selection of the best offspring possible, toward the elimination of hereditary disease, and toward human engineering—"the self-direction of human evolution," as one Progressive-era poster put it. By focusing on the medical dimension of human heredity, we can see that these are constants in the history of biomedicine. Those constants find new expression in each era of our history. They have to be understood in their own context. This perspective dissolves the sense of inevitability and progression from our narrative of medical genetics and breaks our preoccupation with state control. Contemporary genetic medicine is not the fulfillment or completion of the science's promise but rather another stage in the evolution of a field that cannot exist outside of a social and cultural context.

I follow a small, evolving community of American scientists and doctors through the twentieth century, from the first stirrings of Mendelian genetics after 1900, through the building of a profession of human genetics around midcentury, up to the science-fiction achievements of recent biotechnology and the Human Genome Project. They are a diverse group of eugenicists, psychologists, geneticists, zoologists, physicians, statisticians, and public health workers. Many of these men and women will be unfamiliar even to scholars in the field; few are household names. I have traced their stories and contributions through their published work, both technical and popular; by reading their mail, memoranda, and other archival documents, as well as newspaper and magazine articles, biographies, and obituaries; and, for the more recent figures, by talking to them and those who knew them. Though their values and skills were diverse, they shared the belief

that they could and should use their knowledge of heredity for the benefit of individuals, families, and society. They sought to integrate the science of heredity with the humanitarian aims of public health and medicine. A utopian spirit pervades their words and work. Heredity, they believed—and believe—is the foundation of human identity. Understanding it, manipulating it, controlling it can improve our lives.

As we follow them, medicine becomes genetic and genetics becomes medical. The narrative of the medical turn in human genetics implies that genetics colonized medicine; physicians seem almost passive receptacles for the genetic knowledge that sharpens and mechanizes their conception of disease. But I show that physicians actively imported genetics into their discipline—slowly at first, then with increasing vigor. As I tell this story, eugenics takes on a new role. It is no longer a sticky, noisome residue to be scrubbed off the skin of human genetics before it can go medical. Rather, eugenics is the lifeblood of medical genetics, the very reason genetics appealed to physicians. Science and medicine are equal partners in the formation of this new field. Medical genetics emerges as a true hybrid, not a graft. Another reading of this story, then, is as a case study in the history of biomedicine, with the tensions, negotiations, and alliances between the competing styles and interests of the scientist and the clinician. The hybridization of science and medicine, of course, is one of the defining characteristics of twentieth-century healthcare.

This reading of American medical genetics has two subversive effects, two sides of the same coin. First, by tracing the medical thread through early human genetics, I reveal that period to be less confused and malicious than it has often seemed. The first years of human genetics was not merely "sloppy science" and racist dogma. Much of the medical side of early human genetics was aimed at the same basic goals as genetic medicine today—and even at many of the same targets, of health, personality, and intellect. Obversely, contemporary genetic medicine emerges as being less benign than the public relations campaigns would have us believe. The desire to relieve suffering and to improve ourselves genetically is noble but freighted with social and ethical consequences. The promises of genetic medicine *are* the promises of eugenics.

The genetic approach toward health has enormous power to reduce suffering and improve our lives. But it is more than an altruistic endeavor: it

is also a fascinating set of puzzles, a powerful political tool, and big business. Historicizing the promises of genetic medicine allows us to critically explore the interplay among the economic, political, intellectual, and humanitarian impulses driving genetic medicine. As biomedicine and healthcare become increasingly important in daily life, a healthy skepticism becomes literally vital. It can help us benefit from the powerful new knowledge biomedicine daily produces. As patients and consumers, we must use that knowledge intelligently—lest other interests trump our own.