

Introduction

SCIENCE, SUBJECTIVITY, AND CITIZENSHIP

The novelty of modern biopolitics lies in the fact that the biological given is as such immediately political, and the political is as such immediately the biological given.

—Giorgio Agamben, *Homo Sacer*

Every ethnography has its genesis in the interests and experiences that put an ethnographer on a particular path. The path to this project runs through the Czech Republic, where a set of unexpected encounters introduced me to the idea that public discussions of human genetics in the Netherlands were being framed in terms of national identity. While conducting research in Prague during the summer of 1991, I met a Dutch nurse, Veronica, at a bus stop.¹ Over the course of the summer we became acquainted and occasionally met to have a meal, go for a walk, or attend a concert together. At some point early in the summer Veronica asked me about my work. She appeared baffled by my reference to the anthropology of science and medicine and by the fact that I was conducting research in Europe, telling me that she thought anthropologists studied people in places like Indonesia and South America.² I made several attempts to explain the immunology project about science and popular culture I had been working on and would be returning to in the fall (Claeson et al. 1996; Martin 1994; Martin et al. 1997), but she seemed not to understand the relationship of this work to her conception of anthropology. Finally, I tried another example, pointing out that the U.S. government had recently committed to devoting three billion dollars to the Human Ge-

nome Project, a joint project of the National Institutes of Health and Department of Energy intended to map the entire sequence of the base pairs making up a typical human genome. I explained that such a project would have enormous social, cultural, political, and economic implications in addition to its potential value for science and medicine.³ The genetics example immediately made sense to Veronica. “Oh,” she exclaimed, “you mean the genetic passport.” I had never heard of a genetic passport, so I asked her to explain what she was talking about. Veronica described the genetic passport as something the Dutch ministry of health was considering. She believed that this passport would be an identity card with one’s genetic makeup encoded on it and that it was intended for both identification and health purposes.

The concept of a genetic passport intrigued me. It seemed such an explicit example of biopolitics—the modern project described by Michel Foucault of optimizing and managing individuals and populations in the name of producing the “normal.” Veronica and I discussed the issue of the genetic passport in several subsequent conversations. Over the course of the summer I had an opportunity to meet several of her Dutch friends who visited her in Prague. I asked each of them about the genetic passport. Each recalled having heard about the idea and seemed concerned about its possible development and the kind of surveillance it implied, although none knew whether or not it was under serious consideration. As an anthropologist interested in the production, circulation, and consumption of scientific knowledge, I was curious about the significance of such a concept and how it fit with broader Dutch social life and practices. The idea of a genetic passport intrigued me because of the questions it raised about the relationship between scientific knowledge of genetics and broader understandings of the body as well as of human and national identity. The idea of a genetic passport thus led me to the Netherlands and generated my initial questions.⁴ Why would the Netherlands, or any country, produce an identity card with one’s genetic makeup encoded on it? Why would a national health department, rather than a state department or ministry of foreign affairs, develop an identity card called a passport? Why would the Dutch government be developing and Dutch people talking about a new kind of passport in 1991 when, with the expected implementation of the European Union’s Maastricht Treaty in 1992, borders within Europe were about to be opened and become, at least bureaucratically, irrelevant? What did the concept of a genetic passport say about people’s beliefs concerning the

state's ability or right to see with regard to the bodies of its citizens? What might the idea illuminate about biopolitics and the production of the normal in the context of newly emerging genetic knowledge? What did it say about the contemporary relationships among biology, scientific knowledge, identity, and citizenship? Furthermore, since the idea of a genetic passport had not actively circulated in the United States, its salience in the Dutch context raised important questions about how the production, interpretation, translation, and consumption of scientific knowledge might differ from one national context to another.

Seeking answers to my questions, I discovered that the genetic passport was something of a myth. No department of the Dutch government was planning to develop such a thing. The concept of a genetic passport appears to have been introduced in the Netherlands in 1989 by Huub Schellekens, a prominent Dutch cell biologist, in a Dutch television documentary. This three-part documentary, *Beter Dan God* (Better Than God) (Kayzer 1987), examined emerging genetic knowledge in the context of the history of genetics and especially the history of eugenics.⁵ At the time of my research the documentary was repeatedly described to me as having been extremely popular, one of the most widely watched television programs in Dutch history. The idea of a genetic passport rapidly became part of popular culture, circulating in conversations among Dutch people and in popular media (magazines, newspapers, radio, television) in discussions about human genome research and its applications in medical and scientific practices.

At first confounded by my discovery that the genetic passport was a myth, I soon grew even more intrigued. No aspect of social life makes sense outside of the social system in which it operates. The circulation of the concept of the genetic passport in the Netherlands is no exception. Neither is the practice of human genetics itself, which is otherwise so readily decontextualized as a symbol of the universal and a sign of the unmarked cosmopolitan. Indeed, anthropologists have long been interested in myths and other narratives because the themes embedded in the stories people tell about themselves and the world offer important clues to the organization of their cultural values.

The readiness with which Dutch people took up the concept of a genetic passport signaled the centrality of emerging genetic knowledge to how Dutch people imagine the future in relation to science, subjectivity, and citizenship and, moreover, indicates that the ways people grapple with

such issues will likely differ across time and space. Increased knowledge of the human genome bears directly on Dutch understandings of relations between national groups and between states as well as on internal differentiations within a national population. The idea of a genetic passport thus opens the door to larger issues. It raises questions about how contemporary ideas and practices concerning genes are made meaningful in any particular national context and how people appropriate and transform their beliefs and practices as they work to reproduce valued aspects of social life.

As I began investigating genetics in the Netherlands, I learned that the idea of a genetic passport spoke to Dutch anxieties about genetics related to the history of Dutch experiences of the Second World War. Prior to 1994, when the Dutch government began requiring identity cards, people in the Netherlands had been required to carry them only once before: during the Nazi occupation of the country in the Second World War. But people also link the concept of a genetic passport to the war in other ways. When I asked a Dutch social scientist about the concept, he told me he was not very familiar with the idea of a genetic passport but went on to talk about the wartime deportation of Jews from the Netherlands. He said that in terms of percentages, more Jews were deported to concentration camps from the Netherlands than from any of the other countries from which the Nazis conducted such deportations. He explained that many people believed the Nazis were able to deport so many Jews not because the Dutch were more anti-Semitic than other Europeans but because the Netherlands had always been a highly organized society, and this organization facilitated the Nazis' ability to find Jews in the Netherlands. He then speculated that the genetic passport might be another example of Dutch emphasis on organization and social order. I thus came to see that the genetic passport referenced anxiety not just about social disorder associated with war and occupation, but also about the problem of social order and obedience.

Since the end of the Second World War the Netherlands' national borders may never have appeared so penetrable as they do today in the face of contemporary immigration and the ongoing process of European unification, which has involved the opening of internal European borders. In discussing the unification of Europe in interviews, the Dutch people I spoke with repeatedly voiced concerns about the opening of national borders and diminishing control over who and what comes into and goes out of the Netherlands.

The theme of borders is inextricable from the history of the Netherlands because the very shape of the country has been repeatedly reconfigured by draining, dams, flooding, and erosion.⁶ The people I spoke with during my fieldwork were worried less about the possibility of being flooded by water than about the prospect of being inundated by people and things that might dilute cultural identity and national integrity. Although they were virtually unanimous in their enthusiasm for the European Union for its economic potential, they repeatedly articulated unease about the reproduction of Dutch social life. They discussed their anxieties about the possibility of increased immigration in a country that is already one of the most densely populated in the world (Shetter 1987:41). They also expressed fears about the movement of drugs and diseases across increasingly permeable national borders. Finally, they spoke about the importance of maintaining a primary Dutch, as opposed to European, identity, expressing this worry in their attitudes toward the opening of the borders as well as in their desire to hold on to such valued cultural markers as the Dutch guilder, then their national currency, and the Dutch language.

The idea of a genetic passport helped people to crystallize and express their concerns about rapid developments in scientific knowledge and new technologies and their implications for social life in relation to anxieties about what it means to be Dutch in light of Dutch history, recent immigration, and European unification. The concept of the genetic passport, like the popular interest in the *Beter Dan God* documentary, signaled that Dutch people had particular stakes in the development of new genetic knowledge. This book is the result of my having followed these signals.

In exploring these issues throughout this book I will argue that contemporary genetic practices in the Netherlands are powerfully shaped by two highly valued Dutch social ideals: first, a desire for ordinariness; and second, a commitment to tolerance. These simultaneously contradictory and interconnected social ideals are always in tension with one another in that they speak both to a deep desire to fit in and to an imperative to accept difference. The contemporary significance of memories of German occupation and Nazi eugenic science during the Second World War further complicates perceptions of genetics in the Netherlands today. Although that history is part of a longer history of articulating Dutch identity in contrast to Germany, in the context of genetics it both raises the specter of eugenics and offers most Dutch people a particularly well-articulated understanding of national difference widely constructed as “tolerant Dutch-

ness” in contrast to “intolerant Germanness.” Compounding this history is the emergence of newly disquieting ideas about national identity and the future of the nation, ideas related to European unification that also shape the ways many Dutch people perceive contemporary genetic knowledge and practices.

The Netherlands is a place where ordinariness is highly valued, but, at the same time, any attempt to engineer it is met with apprehension and may be challenged by the social imperative to tolerate difference. The history of the Second World War and contemporary anxieties about European unification expand the grounds upon which genomics may be challenged or embraced. The emergence of genetics as big science at the end of the twentieth century, including the possibility of ensuring the production of ordinariness through genetics, has thus created both possibility and anxiety. Indeed, genomics offers a seemingly scientific basis for determining ordinariness while at the same time precisely opening up the arena where it has historically most obviously been in conflict with tolerance.

In the chapters that follow I trace these issues through the everyday experiences of Dutch people as they encounter genetics in their personal and professional lives. By observing this complex mix we will see how biology, citizenship, and identity are inseparably intertwined. The Dutch case thus illustrates how genetics can be a site for articulating national identity and, in so doing, it demonstrates how such phenomena are incorporated into genomics as it is integrated into daily life.

Finally, another central argument of this book is that the field of genetics—refracted through this complex cultural and historical mix—illuminates how scientific practices are deeply tied to the local even as they signal the position of the Netherlands as a quintessentially Western nation that supports and engages in modern, cutting-edge international scientific endeavors. In this sense, the selection of the Netherlands contributes to a vital reconfiguration of what can constitute the field in anthropology, involving an expansion of anthropology beyond its more traditional field sites.⁷ In my book I go a step further to challenge an ongoing tendency to homogenize the West (Carrier 1995; Gupta and Ferguson 1997). The practices that produce this tendency are diverse. In anthropology, where geography has been at the center of the discipline since its inception, this tendency is visible in the frequency with which analyses are framed, either explicitly or implicitly, in comparison with underanalyzed notions of the West. In science studies, research focusing on clinical or laboratory practices often

does not even consider the West as a category of analysis, leaving differences within the reified West uninterrogated.⁸ Challenging the assumptions embedded in these practices is central to my project.

The inclination to reify the West as a monolithic construct is intensified in matters pertaining to science and its implied universality because the power of science itself comes from its ability to obscure its locality. Genetics represents precisely the kind of social practice that people understand as being fundamental to defining the West. People perceive acceptance of scientific principles as a sign of sharing in a common Enlightenment heritage that marks one as modern, cosmopolitan, and thus a member of Western society.⁹ To characterize Dutch genetic practice as locally specific is not to suggest in any way that it is somehow a less rigorous or otherwise inferior type of science or medicine.¹⁰ My point here is to demonstrate the specific local interanimation of science, medicine, and culture in a nation otherwise viewed as a part of a monolith of Western modernity.¹¹ Concomitantly, we will also come to see that in the age of the European Union and of international genetic medicine, what exactly it means to be Dutch is itself in transformation. By focusing on the lived experiences of Dutch people as they work in and encounter genetics in their daily lives, we can see how ideas about the normal, citizenship, and Dutch identities emerge within a dynamic social field of specific cultural values. Thus, in the local practice of the global enterprise of genetics in the Dutch context, the notion that there is any such thing as a monolith of Western modernity or of genetics dissolves.

CONTEXTUALIZING GENOMICS

Since the late 1980s those of us who live in much of the industrialized world have witnessed a major shift in scientific priorities. This shift can largely be glossed as a move away from cold war preoccupations with defense-related science—especially physics—toward a contemporary focus on the life sciences, particularly genomics and bioinformatics, and their potential applications in medical practices. The shift places the body at the center of scientific inquiry both as the source of research materials (DNA, family histories, etc.) and as a site for intervening in biological processes. Biology emerged as so-called big science in 1988, when the U.S. government unprecedentedly made funds available for life science research by funding the Human Genome Project. Its simultaneous emergence with the ascendance of neoliberal market values combined with a

largely private, profit-driven American health care system and global pharmaceutical industry perhaps ensured that biology also would become big business. Today, the still-expanding biotechnology industry is a highly capitalized, multibillion-dollar segment of the world economy.¹²

The contemporary significance of expanding knowledge in the life sciences means that examining the production, circulation, and consumption of scientific knowledge and medical practice is an essential component of understanding the dynamics through which power is produced and exerted in relation to persons and bodies in contemporary social life. At the beginning of the twenty-first century people in a wide range of national and cultural contexts are being offered a powerful new theoretical understanding of life and the relatedness of all species, including the human species, as well as a set of practical interventions into human biology and reproduction that aim to exert new kinds of control over the production of persons. In those places where genetic knowledge and its associated technologies are socially available and culturally salient a wide range of people have participated in the production of highly mediated discussions of utopian and dystopian fantasies about genomic futures. At once people are presented with hopeful visions of a future of regenerative medicine supporting longer and healthier lives, while they also express fears of a brave new world of genetic discrimination, new eugenic practices, genetic passports, and increasingly narrow definitions of what constitutes an acceptable member of the human race.¹³ The concept of the genetic passport plays on just this double vision. It was imagined as a card that could facilitate what is now called personalized medicine—the idea that genetic knowledge could facilitate physicians’ ability to tailor people’s medical treatment to the specifics of their genomes. At the same time, a new identity card with detailed information about a person’s biology raised the specter of increased surveillance and social control.

The history of the Netherlands easily establishes the country within a paradigm of the scientific heritage of the Enlightenment. Since at least the times of the Dutch pioneers of science Christian Huygens (1629–95) and Anton van Leeuwenhoek (1632–1723) Dutch society has fostered and embraced scientific pursuits and international scientific collaborations.¹⁴ Today, the Netherlands maintains a highly developed and highly sophisticated cohort of scientific and medical experts who actively participate in an international community of genetic researchers and practitioners. Through its national health care system, the Dutch state also maintains an

extensive network of genetics centers where genetic information and services are efficiently delivered to broad sectors of the population.

During my fieldwork it became clear to me that contemporary genetics opens up a space in which people produce diverse narratives about this new knowledge. There is no single story about genetics in the Netherlands; its meanings are contested and negotiated within and across social domains. For most Dutch people, genetics evokes a range of potent and sometimes ominous associations. These stories most immediately involve the dynamics of ordinariness and tolerance, the legacy of the Second World War, and contemporary concerns about boundaries between persons, groups, species, and nations. For a laboratory geneticist, however, genetics also means using scientific and technological processes to read the body from the level of chromosomes and DNA. This story is largely one of using genetics to decode the body. For a clinical geneticist, genetics involves diagnosing, classifying, and counseling patients and their families. This is a story that revolves around solving complicated medical problems and highlights the fluidity among the worlds of science, medicine, and everyday life. For patients, genetics involves negotiating the meaning of the body with scientific and medical professionals as well as with those in their various social networks. This story implicates myriad complex social and personal issues ranging from making reproductive decisions to construing the impact of genetic diagnosis upon identity. Of course, these subject positions are not mutually exclusive. They are themselves complex and crosscutting in that individuals may simultaneously occupy more than one subject position in any given context. An individual might at once be a Dutch clinician or a Dutch person who becomes a patient when pregnant or when a family member seeks some kind of genetic testing. Thus, in any specific context a particular individual may bring multiple perspectives to how they understand the meaning and significance of genetic knowledge and practice.

THE ANTHROPOLOGY OF SCIENCE AND MODERN LIFE

The social transformations set in motion by new genetic knowledge in the Netherlands are deeply connected to social processes associated with modernity. Foremost among these processes in my analysis are the interrelated phenomena of biopolitics, normalization, and citizenship. The genetic passport directly raises the question of why Dutch people used a concept so closely associated with citizenship and national identity to

express their concerns about new genetic knowledge. Passports, of course, are a state-sponsored instrument for defining and bounding national identity. Genetics operates similarly at a different scale to define and normalize biological identity at the molecular level. A national passport answers the question of who counts as *legally* Dutch; the idea of the genetic passport speaks to the question of who is *biologically* Dutch. In this one example, then, we see biopolitics writ large.

Biopolitics operates most powerfully through its delineation of the contours of the normal. Much of contemporary human genetics involves conceptualizing the body at the molecular level as a means of understanding and producing representations of human normality. Indeed, the Human Genome Project aimed to produce a representation, in the form of a map, of a single, archetypically normal human genome. The idea of normal is threaded through genetics in both theory and practice and is prevalent in the molecular genetics of the Human Genome Project and genetic research and practices focused on human health.¹⁵

But the normal is a slippery category. Since the normal is produced only in relation to the abnormal (Canguilhem 1991), it is always twinned with the abnormal or the pathological.¹⁶ This twinning is repeatedly visible in discussions of the Human Genome Project, in which one of the central images of the rhetoric its proponents employed was “the idea of a base-line norm, indicated by ‘the human genome’” (Keller 1992:294). In mobilizing this image of a norm, these geneticists thus defined health “in reference to a tacit norm, signified by ‘the human genome,’ and in contradistinction to a state of unhealthy (or abnormality)” (Keller 1992:295). There also is a tension in the concept of the normal involving its characterization, on the one hand, as “an existing average” (which can be improved upon) and as a “figure of perfection to which we may progress” (Hacking 1990, cited in Keller 1992:298). The ambiguities embedded in the concept of normal are confounded in the context of contemporary molecular genetics, where at the same time that the concept of the normal plays a central role, in fact variation is the norm.¹⁷

In the Netherlands the scientific process of genetic normalization exists in constant dialogue with powerful, salient local Dutch social practices of normalization. Dutch people frequently express attitudes about the importance of normality in the concept of ordinary (*gewoon*), a positively valued concept constantly employed in daily life. The common saying, “*Doe maar gewoon, dan doe je al gek genoeg*” (Just act/do/be ordinary, then you are

already acting/doing/being strange/crazy enough), for example, expresses the emphasis on ordinariness in Dutch social life. In chapter 1 I explore how contemporary Dutch society is imbued with the concept of *gewoon*: it is used in everything from television advertisements to comments parents make in their attempts to encourage good behavior in their children. These processes of normalization locate genetic practices in the cultural and ideological specificity of the Netherlands, where the ability to *do* ordinary can easily be understood as consonant with *being* Dutch. Thus, in the Dutch context the normal and the ordinary work simultaneously as Foucauldian regulatory ideals and also as explicit terms people use every day to articulate cultural values. By recontextualizing the production and application of new genetic knowledge in this way, we will see how taken-for-granted the structures of normality are in everyday life and in biomedicine.

The chapters that follow explore the force of culture in the processes through which people are working out what counts as normal as they encounter genetics in daily life. They reveal the ways the future is being worked out in the present.¹⁸ As we see Dutch researchers, clinicians, and others working out this future we will see that what counts as normal, even in the domains of science and medicine, is highly unsettled. The Dutch case shows not that people accept the idea of a single norm but that contemporary genomics is a space in the present where people are establishing the tolerable limits of human biological variation for the future. In so doing they are also imagining the tolerable limits of citizenship.

Citizenship, understood as a form of belonging codified in law and experienced through the formation of national identity, lies at the core of the modern state.¹⁹ Questions about biology and citizenship raised by my encounter with the idea of a genetic passport were at the heart of my entry into this project. Many citizenship and nation-building projects have had a biological component, referencing such concepts as blood and race (Balibar 1991; Heath et al. 2004; Rose and Novas 2005). This link between biology and nation suggests that questions of citizenship would inevitably surface in the context of new knowledge about biology.²⁰

The complexities and contradictions of twenty-first-century citizenship are broadly inflected with concerns about the biological (see especially Heath et al. 2004). This complex terrain has eugenic potential but is also a site of “new forms of power, knowledge, and embodied discipline, along with novel rights and responsibilities” that Deborah Heath, Rayna Rapp, and I describe as “genetic citizenship” (2004:152).²¹ In the chapters that

follow I invoke the concept of citizenship both to talk about rights and responsibilities and also to explore those aspects of citizenship that involve often unarticulated cultural frameworks of belonging, including notions of biology, that connect specific individuals to a specific state, nation, and identity. As relations between citizen and state become refracted through the prism of genetics, this new biological knowledge suffuses the genomic futures both of individuals and of the nation.

FIELDWORK AND METHODOLOGY

This book is based on a year of multisited ethnographic fieldwork in the Netherlands, conducted between August 1993 and August 1994. My primary field sites included one of the eight genetics centers in the Netherlands, two high schools, and a community center for people over the age of fifty-five (a category of people known in the Netherlands as *vijf-en-vijftig plussers*). In addition to participating in and observing activities in these sites I conducted more than 110 in-depth interviews.

The field is never as bounded as the delineation of clinic, high school, and community center might imply. I also sought out a number of people who had specialized knowledge about genetics in the Netherlands: a director of a center for bioethics; the staff of an umbrella organization coordinating activities of the support groups representing various genetic disorders; a historian and a cell biologist who coauthored a history of eugenics; the producer of a ten-part television documentary about genetics that aired while I was in the Netherlands; and a staff person from the Society for the Protection of Animals involved in a campaign against genetic manipulation in animals.

I also learned much from participating in the routines of daily life and the numerous informal conversations and experiences such activities entail. Though it is impossible to detail the innumerable daily occurrences that ultimately inform the way one comes to understand the meanings embedded in daily activities, some of the experiences I had stood out for the way they informed my understanding of the Netherlands and of genetics. I remember encountering Dutch bureaucracy in the process of applying for a residence permit; I seemed to be the only American among what seemed to be over a hundred people likely of Turkish and Moroccan origin who, like myself, were seeking the right to be in the country. I traveled widely by both bicycle and public transportation, taking in the landscape, the weather, and the efficiency with which one is able to get

around the country. Shopping at local stores and outdoor public markets, going to museums, attending an open house at a local community center; engaging in social activities with a wide variety of people, sharing an apartment with a Dutch university student, and participating in holiday activities such as the arrival in the Netherlands (by boat, from Spain) of Sinterklaas (St. Nicholas or Santa Claus) with his Moorish assistant Zwaarte Piet (Black Piet) all informed my understanding of the Netherlands. Such open-ended experiences of everyday life are a central component of ethnography. They also provide an indispensable framework for broadly contextualizing specific practices of genetics in the Netherlands.

Over the course of any given week I would find myself involved in a diverse set of activities through which I came to understand how genetics was embedded in everyday life in the Netherlands. Most mornings I would ride my bike to the genetics center, where I would join one or more clinicians as they examined and consulted with patients or sit in on meetings of clinicians as they worked to diagnose the puzzling array of symptoms they had encountered in particular patients during the previous week. Some days I would interview a clinician or laboratory geneticist. Several days I observed the local obstetricians performing amniocenteses, listening to the interactions between and among the medical specialists, the pregnant woman, and the person(s) accompanying her (usually her partner) as the physician used a needle to draw amniotic fluid from the woman's belly in order to grow and examine the fetal cells contained in the fluid. I would regularly join one of the clinicians at the local teaching hospital, where they spent the afternoon meeting with pregnant women, typically with their partners, who had been referred for consultation with a geneticist. In these meetings I would listen while the geneticist used pictures of cells and chromosomes to explain cell division, conception, and genetic risk. Over a series of Monday evenings I made sure I was home in time to watch *Een Rondje DNA* (A Round of DNA)—a ten-part Dutch television program that aimed to educate people about genetic knowledge. One evening while watching the program I was struck by a description of cell division, conception, and genetic risk that was similar to that given by the geneticist at the hospital. Rather than using the pictures of cells and chromosomes I had seen in the clinics, however, the program used cooked spaghetti noodles to represent genetic material for their intended popular audience. I attended the genetics segment of a biology course at a high school and volunteered at a community center for those over fifty-five. I asked every-

one I encountered—clinicians, researchers, patients, students, retirees, people I met in the course of everyday living—if I could interview them about their experiences with genetics. Many evenings I would take the train or ride my bike to the family home of an individual or, more often, a couple who had generously agreed to share their thoughts about their experiences with genetics. Some of those I spoke with had little formal experience with genetics, having primarily considered it in relation to things they had read or seen in the media. Some were pregnant and being confronted with the possibility of genetic testing, information about risk related to genetic conditions, and the potential to make choices about whether to carry a pregnancy to term. Others were caring for a family member, usually a child, with a genetic condition or were themselves living with such a condition. Still others were engaged with genetics in their work lives as clinicians or researchers.

During my fieldwork in the Netherlands my access to information was uniquely shaped by my distinctive position within the structures of Dutch society. For example, geneticists, above all, those working in clinical practice, repeatedly expressed surprise that an American, especially one from Johns Hopkins University—a major research university with a highly developed medical genetics program—would come to the Netherlands to study genetics. My institutional affiliation granted me a status in their eyes that facilitated my access to information about their activities.

All ethnographic stories are necessarily partial because of the temporal constraints of fieldwork. I was in the Netherlands for only one year, and the people I encountered had stories that began before I arrived and continued after I left. The partial nature of fieldwork was made clear in the context of the genetic centers where I conducted much of my research. The services the centers provide often involve multiple encounters that take place over many months and even years. Even the cases I followed from the first to what was considered the final clinical appointment often remained open-ended with the recommendation that a child who had been the subject of the encounter return for genetic counseling when she or he began thinking about having children.

OVERVIEW

This book takes on the challenge of recontextualizing science by moving from the broad contours of Dutch society and history to the particularities of contemporary genetic practices in specific domains. Three primary

themes repeatedly emerged during my fieldwork on genetics. They are the subject of my first chapter. The Netherlands is characterized by a deeply segmented social structure that promotes and reinforces an ideal of a self-consciously tolerant society. The Dutch, I learned, enable a social ideal of tolerance by bounding and containing difference so as to minimize its social threat. It is within this ideal of tolerance, I argue, that Dutch people construct and manage the meaning of genetic difference. Yet Dutch values about ordinariness and fitting in limit Dutch tolerance. It is impossible to live in the Netherlands, moreover, and miss the powerful and persistent significance of the legacy of the Second World War. Attitudes toward genetics in the Netherlands are deeply informed by Dutch associations of genetic practices with the Nazi program of racial hygiene. This legacy has influenced how Dutch people I met both inside and outside of the genetics centers make sense of genetics today. Chapter 1 thus lays the foundation for a fuller understanding of the broad social dynamics surrounding genetic knowledge and practice in the Netherlands.

In Chapter 2 I examine contemporary discourses about the significance of new genetic knowledge and the institutional framework through which Dutch people encounter that new knowledge. It is within and in interaction with these highly integrated institutional networks, involving clinics, research and diagnostic laboratories, and departments dealing with psychosocial problems associated with genetics, that human genetic knowledge and practices are produced and reproduced in the Netherlands. Nowhere is the production of that knowledge more evident than in the centers that form the basis of my inquiry in this chapter.

Specific Dutch encounters with genetic knowledge and practice are the focus of my investigation in the subsequent chapters. In chapter 3 we see the most vivid illustrations of normalization at work in the dynamic production of genetic diagnoses within and beyond the clinic. I argue here that the clinical practice of genetics in the Netherlands is produced in a convergence of medical practitioners' desire to identify and pathologize difference and the tensions embedded in Dutch commitments to both tolerance and ordinariness.

In chapter 4 I turn to religion, showing how the Dutch medical geneticists with whom I worked engage ideas and values about the relationship among religion, biology, and the geographical location of religious communities in developing clinical diagnoses. I also explore how religion in the Netherlands functions in the popular imagination as a means of under-

standing the dynamic through which local ideas about geography, social practice, biology, and religion converge with scientific knowledge in producing clinical interpretations of the body.

My final chapter is a case study of a nonprofit group that gained national attention as it articulated concerns about developments in genetics. This chapter highlights the centrality of the body and identity in popular constructions of the significance of genetics. It also demonstrates that these constructions develop out of contestations over the meaning of the body and identity within and across various social domains, as is clear in the startling visual images of human-animal hybrids that highlight the production and dissemination of specific interpretations of the meaning and value of genetic practices.

Throughout this book readers will come to see the complex processes through which local culture and scientific and medical practices mutually engage, contest, and inform each other. Together, these processes will highlight the multiple ways the local production of scientific and medical knowledge of genetics and its application in practice intertwine with history, religion, geography, and political economy to produce Dutch identities. In so doing, these chapters ask one to rethink prevailing concepts of modernity, science, and the West. For as one comes to see how embedded genetic knowledge and practices are in everyday life in the Netherlands, one realizes that genetics cannot be extracted from its national and historical contexts. Research that does not take into account these contexts either misses an important part of the story or relies on uninterrogated assumptions about modernity, science, and the West.