CHAPTER 10 Genetic Citizenship

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Since the inception of the Human Genome Project both biomedical practice and popular perceptions have been increasingly "geneticized" (Lippman 1991): a rapidly expansive array of human differences, including health differences, are coming to be understood as genetically influenced or controlled. This widely distributed shift in perspective has traveled across and knitted together complex networks of association linking activists, scientists, politicians, and corporate interests in the collective transformation of the public sphere. In this chapter we outline these incipient developments, and draw out their implications for understanding the parameters of what we refer to as "genetic citizenship."

We argue that the biotechnical reconfigurations of both genetic science and the public sphere have created a significant locus for an emergent "ethics of care" (cf. Morris 2001). We further argue that these practices challenge conventional notions of a divide between lay people and experts. With extensive new arenas of everyday life now open to both personalized eugenics and official regulation, these emergent networks have also given rise to new forms of democratic participation, blurring the boundary between state and society, and between private and public interests. This transitional technosocial terrain is constituted under the shadow of global markets in pharmaceuticals and health care, and considerable public and private interests in containing health-care expenses. It surely has the potential to call forth eugenic practices at the individual level. Yet it is at the same time a site of new forms of power, knowledge, and embodied discipline, along with novel rights and responsibilities.

Mapping Genetic Citizenship

In order to situate the discussion that follows, we first offer some signposts, pointing to several overlapping modes of social analysis that help to shape our appellation "genetic citizenship." We address here selected works in social theory that provide

useful tools in understanding this phenomenon. The literature we have found most helpful has been drawn from science studies, citizenship studies, feminist studies and queer theory, and the ''new social movements.'' Within anthropology, we note the productive convergence of many of these perspectives at the intersection of medical anthropology and the anthropology of science and technology. Collectively, these bodies of scholarship alert us to the terrains of technosocial engagement where emergent forms of public discourse take shape.

The rich and varied science studies literature informs both our present analysis and the work in the anthropology of science that preceded our collaborative venture. Here we briefly draw attention to the overlap and contrasts between two branches of science studies, the first, feminist science studies (cf. Haraway 1994), the second, actor-network theory (ANT) and its variants (cf. Law 1992). Both schools of thought share the following key concepts. The first is the conviction, albeit from decidedly different perspectives, that technoscience embodies the relationship between knowledge and power. Latour (1987), in the classic actor-network theory textbook *Science in Action*, asserts that ''Science is politics by other means.'' Feminist scholars of science studies, including feminist actor-network theorists, have paid close attention to the gendering of science, underscoring the ''invisible work'' of women and others that is critical to technoscientific networks of association and their claims on progress. (The term *technoscience* here signals the inextricable interdependence between, and joint constitution of, technology and science.)

This leads to a second shared perspective, a focus on the interdependence of or the blurring of the boundaries between technoscience and the rest of society. So, while acknowledging that power relations infuse scientific method, objects of study, and research findings, ANT and feminist science-studies scholars stress that these relations of power are intrinsically grounded in daily practices. Actor-network theory delivers a mandate to study technoscientific networks wherever they lead, for example, beyond the laboratory.

The third concept is an emphasis on the centrality of social-technical ''networks of association'' or ''cyborg'' relations between humans and nonhumans. Both actor-network theory and feminist science studies highlight the ways in which knowledge production rests on the relations between humans and their tools, or nonhuman interlocutors. When we follow science studies' dictum to ''follow the scientists,'' we will necessarily encounter an array of both mundane and cutting-edge tools, such as faxes and photographs, as well as engineered mice and bioinformatics databases, all of which form part of the international flow of technoscientific knowledge and power.

The mandate to study technoscientific networks wherever they lead, which dovetails with recent anthropology's methodological move toward multi-site research, also evokes Foucault's emphasis on the ''microphysics of power.'' Our study of genetic discourse and practice is informed by the notion that power is widely dispersed through all levels of society, and that biological knowledge in its many manifestations is both productive, and productive of resistance (Foucault 1979a, b). Many scholars in the social sciences and the humanities have been influenced by Foucault's suggestion that modernity rests on a shift from the absolutist power over life and death by monarchical structure, to the management of life and death as an aspect of dispersed governmental relations: the subjects of the governmental state

increasingly have obligations to live (and to die) in relation to the interests of the population being governed.

The discipline and health of the body, including "technologies of the self," both objectify and subjectify modern peoples. Thus, practices of hygiene, fertility enhancement or limitation, reproducing or not reproducing, and regimens of health are aspects of what Foucault calls "biopower," which signals the association between whole populations and the "anatomo-politics" located in the embodied practices of individuals. With the geneticization of both biomedical practice and popular consciousness, we note the emergence of a genetic "micro-anatomo-politics" (Flower and Heath 1993) with identities marked and subjectivities inscribed at the molecular level. As our ethnographic examples in this chapter indicate, the dispersed power relations that mark processes of genetic governmentality introduce potential for new forms of knowledge and power to emerge at the interstices between science and society.

These conceptual tools have helped us to track the flow and interplay of genetic knowledge across multi-sited fields linking scientists, lay health activists, clinicians, and politicians to one another and to a diverse array of nonhuman actors, from the genes and molecules implicated in particular diseases and the technologies used to study them, to the visual images that circulate within and between variously defined experts and amateurs.

Reconfiguring Activism and Geneticizing Citizenship Claims

In the late 1970s, a group of parents brought their children into the Senate Office Building on Capitol Hill. Their daughters and sons suffered from the wounded, blistered skin caused by a debilitating genetic condition called epidermolysis bullosa or EB. Presenting their infants' chronically blistered bodies to legislators like Oregon Senator Mark Hatfield, these parents had a singular objective: to secure federal funding for basic research on this devastating disease. Senator Hatfield, chair of the Senate Appropriations Committee, would become an ardent ally, who for years to come successfully secured funding for biomedical research by attaching line-item riders to other Senate bills. In 2000, when Deborah Heath interviewed him, Senator Hatfield began by saying that he wanted to "lobby" his interviewer to support efforts to find more resources to treat "orphan" genetic disorders. He then went on to describe in eloquent detail how his encounters with health activists 30 years earlier had galvanized his own lifelong support for medical research funding. This convergence between the needs of those families and the Senator's commitments – activism at the intersection between legislative politics and embodied experience with genetic difference – represents one aspect of what we are calling genetic citizenship.

Deborah had originally heard the narrative about the families' pilgrimage to Washington from research biologists in response to her queries about engagements between scientists and people living with genetic conditions. Deborah heard this iconic account from different researchers on several different occasions. For her laboratory interlocutors, this had become part of the scientists' perspective on how their own identities as genetic citizens came into being, an origin story about how scientific work takes shape, in part, where activism and the state intersect with

laboratory life. Genetics matters on a daily basis to research scientists and health activists, both as they confront and try to affect public resource allocation and as they engage the complexities of their personal and professional relations with one another.

The parents who made their way to the nation's capital formed the core of a lay activist group known as DEBRA (the Dystrophic Epidermolysis Bullosa Research Association). Like so many other genetic support groups, DEBRA began in family desperation: Arlene Pessar, a Registered Nurse with an affected child living in New York City, set up the first mailing lists, contacted sympathetic researchers and clinicians, and brought the EB families to Washington. In 1998, when Rayna Rapp interviewed Miriam Feder, outgoing head of DEBRA, she was told that "parents used their bloody, blistering babies like a battering ram" to capture Congressional attention: a kinship of affliction figured large in this origin story of an extraordinary coalition for research and treatment, with babies' bodies breaching the boundaries between home, state, and civil society. Arlene Pessar subsequently added that Congressmen had "never seen anything like it, all these cute bandaged kids climbing all over their office furniture, crying for attention. It really made a big impact." Members of DEBRA were subsequently instrumental in creating a registry of EB patients' tissue samples, which have been crucial to laboratory research on the disease. In forging alliances with legislators like Senator Hatfield, and with biomedical researchers, members of DEBRA and other genetic advocacy groups are making citizenship claims on behalf of their genetically vulnerable offspring. We argue that the networks of association arising from these alliances are transforming the public sphere as a site for an emerging "ethics of care."

Peter Marinkovich is a dermatologist, a researcher at Stanford University working on a major project on EB (a program funded by the National Institutes of Health), which involves him in clinical work with patients as well as basic research. The website for the Stanford University Dermatology Department provides clinicians and others with a wealth of information about the diagnosis and treatment of the various forms of EB. Dr. Marinkovich has also used the internet as a forum for his commitment to collaborative patient advocacy. He established an interactive EB website that he moderated with Kelly Drewry, a dynamic college-age woman with one of the more severe forms of EB. Sadly, the electronically mediated networks that facilitate our fieldwork also brought us news of Kelly's death in 2001, through an EB listserv called EBmommas.

Formed in 1997, EBmommas was a family-driven electronic self-help group to which mothers and others posted queries and suggestions on surviving daily life with a fragile child: everything from tips on the endless bandaging problems; recipes that pique the appetites of kids for whom swallowing may be an ordeal; intimate conversations about the marital tensions that accompany life with a chronically ill daughter or son. Here, as in so many other cases, the internet has provided novel possibilities for translocal engagements and intimacies, and for the sharing of both biomedical knowledge and life experience among lay advocates, scientists, clinicians, and their ethnographic interlocutors.

Cyborg Politics, Embodiment, and the New Public Sphere

We note the ongoing transformations of twenty-first-century spheres of genetic discourse – some public, some less broadly so – that are enabled and mediated by

information and communication technologies (ICTs), from genetic databases to online forums. These cultural-technical milieus have transformed an older identity politics, creating venues for participatory knowledge-making in which the distinction between the subjects and objects of scientific inquiry are regularly called into question. We must also note, of course, the potential for a widening of the "digital divide" in which expansion of technoscientific literacy among many increases the exclusion and isolation of those without access in both rich and poor countries.

The web and other social-technical organs of the cyborg body politic instantiate the complexities and contradictions of twenty-first-century citizenship. We maintain that these human/nonhuman interfaces constitute an electronically mediated variant on what Habermas (1989) called the public sphere. This arena is constitutive of the multivocal, densely imbricated relations where claims to citizenship blur the boundaries of inclusion and exclusion, whether between lay and expert, or, in the cases that we study, between the "normal" and "pathological." Indeed, it is precisely the breaching of divides between the genetically disordered and their scientific, medical, and political allies that beckons us to develop the idea of "genetic citizenship."

Classical studies of citizenship have focused on the individual autonomous subject as the rights-bearer within a given nation-state. Yet, as much feminist critique has pointed out, the universal claims of citizenship articulated in classical political theory too often presume a male elite subject on which to construct their universalist arguments. By contrast, contemporary citizenship studies, influenced by feminist critique, point toward contested relations and shifting "postmodern" subjectivities. They are particularly attentive to those whose domains may be global, transitional, or transnational rather than fixed (Ong 1999). The requisite attention of citizenship claims to rights and obligations is conjoined in this literature with an emphasis on recognition and respect, all refracted through a pluralistic lens. Productively reworked by feminist scholars (Fraser 1997) and queer theorists (Bell and Binnie 2000), citizenship seen from these perspectives denotes a multivocal politics of bodies and identities – and their attendant struggles – rather than claims to unity or universalism that efface difference.

Embodiment, difference, and citizenship claims are, of course, long-standing foci of feminist activism, which intersects and energizes many projects in the realm of both health and disability mobilization. More recently, some feminists have also offered political critiques that highlight the implicit masculinism of the normative "independent contractarian citizen." Pointing to the dependency that characterizes long stretches of the human life cycle, feminist critics have analyzed the exclusion of those associated with dependency, whether as care-givers or receivers of care (Kittay 1999).

These contributions by feminist and queer theorists have been fruitfully augmented by work closer to our own realm of inquiry from two directions. Investigators of the AIDS pandemic have highlighted the importance of struggles to gain insider status among scientists, clinicians, and policy-makers. And disability studies analysts have stressed the importance of coalition politics that enable people directly affected by medical, legal, and educational policy to make claims on decisive power. Collectively, these discussions of health/body activism highlight the importance of quite radical claims on civil rights for those whose stigmatized standing is often subject to daily discrimination and prejudice: "Nothing About Us Without Us," as the Disability Rights movement has proclaimed (Charlton 1998).

This insistence on the intimate space of embodied difference as a terrain of public discourse has, of course, been central to theories of sexuality, especially queer theory. Ken Plummer's (2001) notion of "intimate citizenship" usefully points to the significance of bodily and sexual identities as they shape demands for rights and public recognition, which not only explicitly affect sexual minority constituencies, but also potentially affect us all. His work is particularly sensitive to the technosocial mediation of intimate experiences now routinely made public via electronic means. The public mediation of intimate difference is of key concern to us in our investigation of contemporary geneticization. Likewise, many forms of women's activism have transformed the public arenas within which citizenship is recrafted (Yuval-Davis and Werbner 1999).

Building on these diverse literatures, we want to illuminate the emerging arenas of public discourse that link differently embodied subjects to one another. We contend that it is "genetic citizenship" that connects discussions of rights, recognitions, and responsibilities to intimate, fundamental concerns about heritable identities, differential embodiment, and an *ethics of care*. Recent discussions frequently link the notion of an ethics of care to Michel Foucault's notion of "technologies of the self," or of the "care of the self," and to postmodern theories of subjectivity (Foucault 1986). But in the Anglophone literature the concept also has its origins in feminist moral philosophy, from Carol Gilligan's work on moral development in the 1980s to more recent scholarship (cf. Morris 2001). We want to argue for the value and complementarity of both approaches.

Biopower, Advocacy, and the Pursuit of an Ethics of Care

In the early twenty-first-century United States, the state's resources and regulatory power, and its role in caring for the health and welfare of its citizens, are volatile issues. And these are unevenly distributed. In the US, beyond the realm of laws and regulations, health care is marked by the influence of a market-driven economy, vested in blue-chip pharmaceutical giants, expanding health maintenance organizations (HMOs), and roller-coaster entrepreneurial biotechnology companies. In the midst of widespread dissatisfaction with the growing corporatization of medical care and rising costs – coupled with an inadequate insurance safety net – health and health care have become sites of political struggle and desire. Indeed, some of the most potent and vociferous social movements of the last two decades involve health-care demands: the women's health and the AIDS activism movements have both combined trenchant critiques of bureaucratic paternalism with demands for concrete transformations in the ways pharmaceuticals are tested, and medical services distributed and delivered.

Yet the claims of these movements have been more radical than this list of activities implies, for they have also demanded the recognition of their desires – for respect, for experiential authority, for inclusion in the research and design of medicines and medical policies. Recognition demands have not conventionally been associated with medicine, yet they are increasingly in play as various constituencies use their "patienthood" as sites to describe health diversity and the needs it generates. This is surely the case across the wide array of genetic advocacy groups discussed below.

Nor are they alone. Increasingly, large and potent health-based social movements, like that associated with breast cancer, have adopted and extended strategies whose goal is to transform therapeutic and bureaucratic processes in light of their lived experiences. And the language and technologies of public health have been engaged by many social movements, running the gamut from extreme left to right, that focus on dilemmas and desires of embodiment. There is often a productive tension between the use of the statistics and technologies of public health and the demand for demedicalization of their political concerns, which has been deployed by activists working for reproductive rights, gay, lesbian, bisexual and queer rights, and some aspects of anti-violence and human-rights movements.

Under contemporary US conditions, a demand for ''respectful health care as a right'' has a utopian and highly political edge. As such, it is loosely congruent with what are often grouped under the rubric of the analysis of ''new social movements'' – a label developed in the 1980s to describe collective demands surrounding issues of the quality of life, the colonization of private life by market and state, and identity politics constituted around cultural resources and rights to specificity and difference (Laclau and Mouffe 1985). New social movements theory has addressed the limits of conventional class-based analysis, insisting on the primacy of multiple and new social subjects produced by various political crises of modernity. Health activism can be usefully viewed through this optic, especially when claims for recognition and resources proceed through identification with highly specific forms of embodied difference, for example, breast cancer or genetic disorder activism. Likewise, citizenship claims have creatively been made on behalf of disability rights: while modern medicine is in large measure responsible for developing technologies and protocols that have helped to keep many people with disabling conditions alive and well, it has also produced a powerful set of discourses and practices that entrap disability as if it were an exclusively medical category of limitation. Disability rights activists are highly diverse in their embodied experiences and needs (e.g., a spinal cord injury produces quite different challenges to daily life than does deafness or mental retardation). But disability activists are united in an insistence that it is social prejudice rather than physical impairment that constrains their ability to lead fully actualized lives. While health activists often make demands for increased access to medical resources, disability activism is frequently characterized by an opposite strategy: escape from medical definitions to an insistence on political and civic entitlements has produced a distinct and potent agenda.

Alongside the challenges they have posed to biomedical practice, all of the activist constituencies we have indexed have also benefited from and contributed to the use of technoscientific resources as icons and tools of their political projects. Indeed, we are arguing that understanding the dangers and benefits of genetic citizenship requires attention to an emergent public sphere which can only be accessed and understood through the lens of technosocial relations. ''Intimate citizenship'' is largely produced through technosocial networks that constitute the public sphere in the Information Age. For example, both self-help forums on the internet and television talk shows perform multiple functions. They are alternately technologies of the spectacle that may serve as both a modern-day confessional, and a means to achieve technologically mediated intimacy, normalizing the pathological body among geographically dispersed, socially differentiated individuals.

At the same time, some social critics have called attention to the collapse of public citizenship into a potentially more narcissistic "public intimacy" in which the confessional mode – on talk shows, and other highly mediated public displays of sexuality, victimization, and dysfunction – substitutes individual stories of empathy and struggle for more social ground. Yet in normalizing pathological states, and providing genres for the performance of intimate struggles as an aspect of public life, genetic modalities also have the potential to reinvigorate and complicate not just personal but also political life. At these multiple sites of embodied difference and discourse, the possibilities for genetic citizenship begin to be articulated.

Our focus on "genetic citizenship" highlights the intersection between individual rights and responsibilities and the public conditions of their enablement. In that complex nexus where issues like "genetic discrimination" by health insurers, or regulatory guidelines for the Americans with Disabilities Act of 1990 are played out, the cast of interested constituencies is large and growing. It includes associations formed around rare single-gene connective-tissue disorders. Increasingly, however, it also includes those organized around common chronic diseases like arthritis and diabetes, which are now understood to have a multi-genetic substrate. This geneticizing world-view is both a condition and a consequence of material advances in the life sciences. Health activists, biomedical researchers, the public funding apparatus, and the recent and dramatic influx of transnational capital into biotechnology are all implicated in widespread geneticization, as people learn to "think genetically," to see themselves in terms of genetic attributes and limits – or as investment possibilities.

As people come to identify with and make claims based on individual or family genetic conditions or risks, prior coalitions may be refigured. Prioritizing genetic identities may lead individuals to assert claims based on their specific, usually rare, conditions rather than for health care more broadly. At the same time, lay organizations like the Genetic Alliance, which we discuss below, seek to bring together diverse genetic constituencies oriented around genetic identities. Of course, in some senses, "everyone" can be described in terms of genetic susceptibility; indeed, we might argue that people with known, albeit rare, genetic conditions serve as what Faye Ginsburg and Rayna Rapp refer to as the "canary in the gemeinschaft" for the forms which more widespread genetic understanding and interventions will take. While there is ample reason to worry about the eugenic legacies into which such "genetic thinking" easily fits, we want to complicate the story.

Genetic Citizenship and its Technosocial Alliances

Our fieldwork illustrates the technosocial networks of association that have arisen as the Human Genome Project has brought molecular biology and medical genetics into public view. The interpolation of US citizens into genetic perspectives through their workplaces, civic lives, and family responsibilities, as well as through their individual health status now and in the increasingly screenable future, produces not only sites for eugenic discrimination, but also locations in which new forms of subjectification and collective activism come into being. Genetic citizenship may sometimes facilitate democratic possibilities, as well as constraining them. At this juncture, cross-cutting alliances and shifting subjectivities among bench scientists,

Washington lobbyists, and lay genetic advocates move beyond the singular solidarities of conventional identity politics. Emerging from these coalitions, genetic citizenship both marks and potentially transcends the medicalized identities of those living with rare and debilitating heritable conditions like epidermolysis bullosa (EB). It also reveals how the workings of contemporary science in society reconfigure traditional boundaries between state, home, and civil society.

One of our aims is to locate new, or newly configured, sites for citizenship and claims on democracy that emerge from the sometimes uneasy coalitions of the present era. As chroniclers of the AIDS epidemic have taught us, health advocates with chronic, life-threatening diseases have had to face the challenges of crafting complex political-economic relations with the state and market in the quest for medical treatment, social services, and appropriate biomedical research. In this process, they have articulated demands for insider status in scientific controversies and claimed credit for contributing to scientific advances. In their coalitional work, a generative mix of public and private resources has been assembled in the service of new citizenship claims.

And state interventions take many forms. Some recent work on EB has been supported by a surprising source: the US Department of Defense. Although EB is a rare heritable skin disorder, its wounds model those of both conventional and chemical warfare. The Army was therefore eager to award a recent grant of 1 million dollars for basic research on EB. Likewise, this ''orphan disease'' attracted funding from the pharmaceutical firm Novartis for an innovative interdisciplinary scientific conference that brought oncological and dermatological geneticists into conversation. This pharmaceutical giant was motivated by the potentially huge numbers of consumers for wound-healing technologies, extending far beyond EB to the enormous market niches represented by burn victims and those with diabetes, as well as the victims of war. Thus a small and desperate genetic disease constituency may, through its researchers, find itself in negotiation with the military and the market.

At present, a growing number of research labs and biotech companies are contending with one another to develop engineered tissues, both natural and synthetic, targeted at wound healing. Organogenesis markets an engineered tissue called Apligraf™ that has been used in clinical trials with EB patients. Another biotech company, Ortec, has a patented composite skin product, OrCel™, that has just received limited FDA approval as a humanitarian device: it is being tested on a small number of EB patients who must undergo repeated hand and foot surgery to ''de-glove'' the scarring of digits that accompanies their disease. The clinical trials run by companies like Ortec and Organogenesis, focused on providing experimental ''compassionate care'' for patients with orphan diseases like EB, undergird the promise of targeting much larger medical and military markets when and if the product proves successful. At a European conference for connective tissue biologists in 2002, Deborah Heath heard presentations on various models of engineered tissue from several European and US laboratories, many with promise for those living with connective tissue disorders like EB. Still, researchers report that there is currently limited proof of how efficacious this treatment is. Some researchers note that despite the allure of cutting-edge wound-healing technologies, and the ample funding available for such research and development, conventional interventions with animal-skin grafts appear to be just as effective.

This volatile interface of scientific, economic, and medical desires, in which genetic activists encounter the powerful convergence of governance, finance, and technoscience, has recently been recognized within the National Institutes of Health. The establishment of the Office of Outreach to Genetic Support Groups, which collaborates with lay health organizations and consumer groups interested in genetics and genomic research, builds upon the work that NORD – the National Organization of Rare Diseases – accomplished. NORD built a coalition of activists intimately involved with ''orphan'' diseases, who successfully lobbied to have tax regulations and subsidies entered into the Congressional budget that enable pharmaceutical companies to continue to produce unprofitable medicines on which the lives of relatively small numbers of patients depend. NORD's coalition of biomedical researchers and their Congressional supporters was spearheaded by family and patient activists: like other ''orphan'' diseases, including the ''genetic orphans'' from whom we have learned, many activists have told us that ''Extreme and rare diseases yield extremely valuable information about how systems of the body work.'' And, we might add, also about how successful Washington lobbyists and compromise political coalitions work as well. Dramatic stories like DEBRA's bloody-baby march on Congress, or NORD's subsidy and tax regulation successes, are not hard to find in a country where a line-item budget annually determines NIH funding anew, and public support for funds that will go to any particular program must be shepherded through the budget-making process by sympathetic legislators. Indeed, lobbying Congress (''advocacy awareness'' in the language of the tax-exempt nonprofit groups who regularly visit Capitol Hill) is virtually built into relationships between US scientists, clinicians, and what we might call their genetic constituencies. For example, at NIAMS (the National Institute of Arthritis and Musculo-skeletal Diseases), researchers brief interested constituencies such as the Coalition of Patient Advocates with Skin Diseases and the Coalition for Heritable Connective Tissue Disorders before these groups make their annual appeal to legislators. Successful health-advocacy groups may well have begun as ''mom and pop'' operations around the kitchen table of a family with a sick child, but if they are to succeed, they eventually ''go national'' and ''go professional'' as well. This ''corporatization'' of grass-roots voluntary associations represents not merely assimilation into early twenty-first-century capitalist culture, but also a strategic intervention, a move to gain access to resources.

Much of this national, professional, and corporate coalitional presence is ''business as usual'': a nonprofit group organized around small numbers of interested and desperate participants must, by definition, find allies and create coalitions if its modest cause is not to be eaten up by larger and more publicly visible ones. Nonetheless, we suggest that out of that professionalizing, nationalizing movement to wrest publicity and allocations from Washington, unanticipated claims on democracy may also occur.

''Genetic citizenship'' looks somewhat different when viewed from the perspective of systems of health care and scientific funding outside the US. For example, DEBRA was largely modeled on DebRA UK, a British genetic activist group that was formed a few years earlier. In the United Kingdom, where citizen groups do not lobby Parliament because its budget is not amenable to their influence, the organization has succeeded in attaching DebRA's cause to a series of corporate charities and lotteries; the late Princess Diana was their most celebrated sponsor. In the UK, the GIG (Genetic Interest Group), a coalition not unlike the US Genetic Alliance has

recently grown in influence, allying itself not only with the Medical Research Council (the UK's equivalent to the NIH) and the Wellcome Trust (which contributed the lion's share of funding toward UK Human Genome mapping), but also with the Genetic Group of the European Union. Like France and other EU nations in which rare disease constituencies tend to be organized from the top down by governmental health bureaucracies, rather than from the bottom up, as has historically been the case in the USA, the GIG and its peer organizations find themselves increasingly involved in setting health and research policy as the EU recirculates some of the NORD strategies borrowed from the NIH. Thus many of the issues to which our label of genetic citizenship applies have specific global aspects, at least in some of the rich countries of the North.

In the US, parental efforts to advance research on EB have focused on public funding: early on, they convinced the NIH to hold a scientific conference and to fund the creation of a registry of patient tissue samples. A registry is both an invaluable tool for scientific researchers, collecting the material they need to construct research data, and an actor network around which the recruitment of interested new scientists looking for "hot" topics and new sources of funding may coalesce. The EB registry became a model for how activists and the NIH have catalyzed researchers to work on other rare but scientifically significant diseases, because it demonstrated the value of centralized access to the material means of scientific knowledge production. Later generations of genetic citizens have adapted this model to fit the specificities of their own situations and objectives.

The Familial Dysautonomia Foundation, for example, raised enough money through affected families and their supporters to fund projects at a major Boston academic laboratory in search of "their" gene (called the FD gene). This dysfunction of the autonomic nervous system (ANS) affects most bodily systems, yet the ANS itself remains poorly understood. Thus researchers were eager to win Foundation funding, hoping that work on this rare condition would clarify other aspects of the ANS. While the Boston researchers quickly found a linkage (in the region of the gene), it took over nine years to find the gene itself, because it turned out to be a splicing defect in the RNA rather than in the DNA, and such entities remain relatively little studied. At the last minute, and under the influence of both the huge bioinformatic public database generated by the Human Genome Project and the biotech corporation Celera's race to outstrip the NIH in declaring the first "map" of the entire genome, an upstart New York lab also found the FD gene. Recognizing the importance of this scientific competition, the FD Foundation is now funding both labs in the quest for animal models and gene therapies. It is also attempting to pioneer non-exclusive patent rights so that both labs and all affected families may benefit from new discoveries.

The case of the Genetic Alliance, which changed its name from the Alliance of Genetic Support Groups in 2000, powerfully illustrates this rapid flexibility of genetic citizens. Founded in 1986, the Alliance brought together a super-coalition of more than 200 genetic lay organizations to provide support to affected individuals and their families. Since its inception it has mushroomed into an organization that coordinates a wide range of activities including, but not limited to, peer support, lobbying, and innovative physician education. The Alliance's own statement on the motivation to change its name demonstrates the unexpected trajectories taken and

social formations emerging today through science and culture in action. They explain their name change as follows (http://www.geneticalliance.org):

> A central realization that emerged during strategic planning discussions was that our founding name, ''Alliance of Genetic Support Groups,'' was no longer an accurate representation of who we have become over the past 14 years. In 2000, this organization is much more diverse than a coalition of support groups. We have become a coalition of consumers, professionals, public agencies, biotechnology companies, genetic diagnostic clinics, public health departments, and children's hospitals, to name a few. In recent years, newer consumer groups have expressed ambivalence about joining the Alliance because they saw themselves as foundations, research organizations, advocates or tissue registries with a wide range of services including, but not limited to, peer support.
>
> SO . . . Because our membership includes all the stakeholders,
> Because we are a strong Consumer Voice
> Because our name needs to say Who and What we are . . .
> We decided to change our name to the Genetic Alliance . . .

As Sharon Terry, Alliance board president and mother of two children with a rare genetic condition, has said, ''we're not a bunch of parents crying into our coffee cups.'' In addition to coordinating activities among genetic lay advocacy groups, today the Alliance engages in a myriad of diverse activities, including the participation of members in basic research and taking places on national advisory boards that aim to reform the process of informed consent. The Alliance works to evaluate and monitor internet resources on genetic disease (a huge and technologically sophisticated task). Its recent efforts include participation in incipient research at the Massachusetts Institute of Technology and the NIH in constructing the Haplotype Map, or ''Hap Map'' (http://www-genome.wi.mit.edu/media/press/pr_hapmap.html), an innovative project which hopes to simplify the study of complex genetic disorders and differences by mapping the way that blocks of DNA called single nucleotide polymorphisms (SNPs), are inherited together in large, neat units.

Each new generation of genetic citizens benefits from and builds upon the strategic interventions of their predecessors. The work of early health advocates like the EB families, from their march on Washington to the creation of the DEBRA tissue registry, has formed a model that is both emulated and transcended by today's genetic activists. For example, when Pat and Sharon Terry confronted the 1994 diagnosis of their children with pseudoxanthoma elasticum (PXE), another rare genetic connective-tissue condition, they quickly became activists, building far-reaching networks of human and nonhuman allies. They established a lay advocacy organization, PXE International, with the express purpose of facilitating research that would lead to a treatment for their children's condition, building a coalition among members of PXE families, their molecules, and their family and medical histories as a way of drawing researchers into the coalition as well. In spring 2000, Sharon Terry described their work to Karen-Sue Taussig, explaining that in contrast to the NIH-sponsored EB tissue registry, the Terrys insured that PXE International maintained direct control over affected family pedigrees and tissue samples. The organization links individuals in PXE families, the blood, tissue, and family and medical histories that have something to tell about the condition, and researchers

who seek to develop genetic knowledge. At the same time, by controlling researchers' access to particular parts of the coalition, the Terrys seek to maintain some control over the process of knowledge production itself. They also volunteered in the laboratory of a Boston researcher from 6 p.m. to 2 a.m. five days a week, determined to move the search for the PXE gene into high gear and gaining the knowledge necessary to insure their status as obligatory passage points (Latour 1987) for anyone interested in PXE. In June 2000 Sharon Terry was a co-author on two of the three scientific journal articles announcing the discovery of a gene for PXE. PXE International and the University of Hawaii have agreed to file their application for the PXE gene as co-inventors. The group is committed to ensuring both open access to the gene for all researchers, and preventing royalty fees that might increase the costs to any individual seeking testing for PXE.

Pat and Sharon Terry regularly consult with other lay genetic health organizations in North America, Europe, and Africa, describing "the PXE model" so that others can adopt the strategies they have employed. In the summer of 2002 Pat Terry was invited to describe "the PXE model" at a meeting of First Peoples in Vancouver, British Columbia, so that they too could consider employing such a model in developing relationships with the researchers who so desire their blood. Elsewhere in the global networks where technoscience and genetic citizenship are intertwined, also during the summer of 2002, Deborah Heath interviewed members of an Italian research lab who described a recent visit by Sharon Terry and her two children. In contrast to the EB activists' legislative intervention 30 years ago on behalf of funding for scientific experts, the Terry family's strategies place them*selves* at the center of ongoing technoscientific practice.

Today the Genetic Alliance considers PXE International a model for lay advocacy organizations seeking treatments for rare genetic conditions. The value of lay advocacy group participation, from the perspective of the Alliance, comes from their interest in the condition "from the bench to the bedside" rather than in what happens to be scientifically "sexy" at the present moment for researchers. Nonetheless, to be this proactive is to confront the culture and politics of both technoscience and the "new economy" in increasingly complex, contradictory ways. Democratic impulses often intersect with economic or political forces far removed from a perhaps idealized ethos of grass-roots politics. We note, for instance that the biotech firm Incyte (and several others) are now major funders of the Alliance. Increasingly, the tension between encouraging an expansion of scientific research and the issue of patenting and regulating the distribution of potential royalties confronts every genetic voluntary health group that has collaborated in and funded genetic research.

Genetics in Action

We began this paper by pointing to the ways in which scientific work in the United States today partly takes shape where consumer activism and the state intersect with laboratory life. We have also found cases in which activism has become a significant part of scientists' and clinicians' daily work. For example, in Vermont Alan Guttmacher, a medical geneticist now at the NIH Human Genome Research Institute, put together a coalition of interested organizations, including the University of Vermont,

a library-based book discussion program, and a parent-run lay advocacy organization, which successfully sought funding for a project called the Vermont Community Genetics and Ethics Project (CGEP). Among its aims, this project tries to engage all Vermont citizens in a conversation about the implications of emerging genetic knowledge and to provide the state with the local resources to deal effectively with issues raised by this new knowledge. In Oregon, Geneforum has been using the internet and other modalities to bring citizens' values to bear on the state's genetic privacy law discussions; in Michigan, a collaboration between the University of Michigan, Michigan State University, and Howard University in Washington, focuses on genetics and citizens' involvement, especially among communities of color which have historically suffered abuses in medical research settings.

Side by side with these public projects on genetic citizenship, other new arenas for public moral discourse may be emerging: For example, Fritz Bach, a leading xenotransplantation (animal organs for human transplant) expert, called for a moratorium on his and similar work in 2000. Reflecting on the potential consequences of his work to reconcile pig and human receptors to enable animal organ transplants, Bach is concerned that the unique medical, social, and ethical problems associated with xenotransplantation be addressed before physicians begin using this potential new technology. Moreover, he is deeply committed to engaging a wide-ranging audience in a public discussion of how to resolve these issues: populist and anticipatory bioethics. Bach and other proactive scientist-physician activists work in ways that reconfigure traditional boundaries between science and civil society as they engage ordinary citizens in conversations about the meaning, value, and direction of scientific work and its potential applications in medical practices and wider worlds.

We want to stress that this conversation is taking place in many venues. In Denmark, for example, the government adopted a community consultation model through which genetic policy is actively presented and debated in towns and cities across the nation before laws and regulations are enacted. This policy was much admired by some advocates at the NIH, who tried to adopt it for US usage. New requests for proposals (RFPs, that is, new funding opportunities) now require that some form of community consultation be built into all future human genetics research. And, as mentioned above, the NIH's orphan drug support program served as the model for recent EU legislation establishing consultative patient groups that will help to formulate research and ethics policy.

Here, genetic citizenship indexes both the political economy of state funding and regulation and the unruly aspirations of scientists, health advocates, health-care service providers, and families, sometimes struggling against the market, sometimes seeking, whether ardently or ambivalently, to join it in an effort to imagine other possible futures. We might want to argue, along with Foucault, that in all these examples we see a "genetic panopticon" in active formation. Yet these multivocal strategies to construct a genetic "ethics of care" are widely dispersed, and they engage many new forms of genetic citizenship. As health activists, scientists, politicians, physicians, tissue banks, bioinformatics databases, websites, confessional talk shows, and bioengineered medical devices are brought together to forge innovative "technologies of the self," we also underline that these forms of agency are necessarily part of governmentality as well. The ethnographic instances on which this essay depends all concern extremely rare single-gene disorders. Yet to the extent that the

widespread and chronic diseases of "advanced civilization" are increasingly understood to have a genetic basis, we all have "screenable futures." If "Genes R Us," then the potent and protean coalitions on which our work is based now serve as a vanguard of genetic citizenship for us all.

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