

BIOLOGICAL CITIZENSHIP

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Introduction

A new kind of citizenship is taking shape in the age of biomedicine, biotechnology and genomics. We term this 'biological citizenship'.¹ Since Marshall's (1950) classic essay it is conventional to think of a kind of evolution of citizenship since the eighteenth century in Europe, North America and Australia: the civil rights granted in the eighteenth century necessitated the extension of political citizenship in the nineteenth century and of social citizenship in the twentieth century.² This perspective is useful, to the extent that it breaks with political-philosophical considerations of citizenship and locates citizenship within the political history of 'citizenship projects'. By citizenship projects, we mean the ways that authorities thought about (some) individuals as potential citizens, and the ways they tried to act upon them. For example: defining those who were entitled to participate in the political affairs of a city or region; imposing a single legal system across a national territory; obliging citizens to speak a single national language; establishing a national system of universal compulsory education; designing and planning buildings and public spaces in the hope that they would encourage certain ways of thinking, feeling and acting; developing social insurance systems to bind national subjects together in the sharing of risks. Such citizenship projects were central both to the idea of the national state, and to the practical techniques of the formation of such states.

Citizenship was fundamentally national.

Many events and forces are placing such a national form of citizenship in question.

The nation can no longer be seen as really or ideally, a cultural or religious unity, with a single bounded national economy, and economic and political migration challenge the capacity of states to delimit citizens in terms of place of birth or lineage or race.

Discussions of these challenges have rarely touched on issues of biology, bioscience or biomedicine. But we want to argue that developments in these areas also challenge existing conceptions of national citizenship and that they intersect with all these other challenges in significant ways. And we make a more general claim: specific biological presuppositions, explicitly or implicitly, have underlain many citizenship projects, shaped conceptions of what it means to be a citizen, and underpinned distinctions between actual, potential, troublesome and impossible citizens.

Of course, there have been many discussions of the importance of biological beliefs for the politics and history of the nineteenth and twentieth centuries. But the biologization of politics has rarely been explored from the perspective of citizenship. Yet histories of the idea of race, degeneracy and eugenics, and those of demography and the census show how many citizenship projects were framed in biological terms; in terms of race, blood lines, stock, intelligence and so forth. Thus we use the term 'biological citizenship' descriptively, to encompass all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species. And like other dimensions of citizenship, biological citizenship is undergoing transformation and re-territorializing itself along national, local and transnational dimensions.

Inevitably, in discussing these issues, the spectre of racialized national politics, eugenics and racial hygiene is summoned from its sleep. Such biological understanding of human beings clearly related to notions of citizenship and projects of citizen building both at the level of the individual and of the nation state.

Nonetheless, contemporary biological citizenship does not, in the main, take this racialized and nationalised form. Of course, these forms of biological citizenship that we discuss here are differentially territorialized – as analyses of bio-prospecting and bio-piracy show, not all have equal citizenship in this new biological age.

Nonetheless, the links of biology and human worth and human defects today differ significantly from those of the eugenic age. Different ideas about the role of biology in human worth are entailed in practices of selective abortion, pre-implantation genetic diagnosis and embryo selection. Different ideas about the biological responsibilities of the citizen are embodied in contemporary norms of health and practices of health education. Different citizenship practices can be seen in the increasing importance of corporeality to practices of identity, and in new technologies which intervene upon the body at levels ranging from the superficial (cosmetic surgery) to the molecular (gene therapy) (c.f. Gilroy 2000). A different sense of the importance of the ‘bare life’ of human beings as the basis of citizenship claims and protections is bound up in contemporary transnational practices of human rights (cf. Agamben 1998). And while it is true that many states are once more regarding the specific hereditary stock of their population as a resource to be managed, these endeavours are not driven by a search for racial purity. Instead, they are grounded in the hope that certain specific characteristics of the genes of groups of their citizens may potentially provide a valuable resource for the generation of intellectual property rights, for biotechnological innovation and the creation of what we will term, following Catherine Waldby, *biovalue* (Waldby 2000)

However an analysis of biological citizenship cannot merely focus upon strategies for ‘making up citizens’ imposed from above. The languages and aspirations of

citizenship have shaped the ways in which individuals understand themselves and relate to themselves and to others. Projects of biological citizenship in the nineteenth and twentieth century produced citizens who understood their nationality, allegiances and distinctions, at least in part, in biological terms. They linked themselves to their fellow citizens and distinguished themselves from others, non-citizens, partly in biological terms. These biological senses of identification and affiliation made certain kinds of ethical demands possible: demands on oneself; on ones' kin, community, society; on those who exercised authority. It is this sense of biological citizenship that is most clearly developed by Adriana Petryna (2002) in her study of post-Chernobyl Ukraine. The government of the newly independent Ukraine based its claims to a right to govern on the democratically expressed will of its citizens. And those citizens who have, or who claim to have, been exposed to the radiation effects of the nuclear explosion at the Chernobyl reactor, believed that they had rights to health services and social support which they could claim from that government in the name of their damaged biological bodies. In this context, she argues "the very idea of citizenship is now charged with the superadded burden of survival... a large and largely impoverished segment of the population has learned to negotiate the terms of its economic and social inclusion using the very constituent matter of life" (2002: 5). Biological citizenship can thus embody a demand for particular protections, for the enactment or cessation of particular policies or actions, or, as in this case, access to special resources – here "to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it" (2002: 4). Life acquires a new potential value, to be negotiated in a whole range of practices of regulation and compensation. This is not a unique situation. We can see something similar in campaigns for redress for the victims of Bhopal and in numerous American

examples of fights for compensation for biomedical damage, portrayed in semi-fictionalised accounts in films such as *Erin Brockovich* and *A Civil Action*. Of course, there are very different political, legal and ethical framings in these different locales. But in each case, we can see that claims on political and non-political authorities are being made in terms of the vital damage and suffering of individuals or groups and their 'vital' rights as citizens.

Biological citizenship is both individualizing and collectivizing. It is individualized, to the extent that individuals shape their relations with themselves in terms of a knowledge of their somatic individuality. Biological images, explanations, values and judgements thus get entangled with a more general contemporary 'regime of the self' as a prudent yet enterprising individual, actively shaping his or her life course through acts of choice (Novas and Rose 2000). The responsibility for the self now implicates both 'corporeal' and 'genetic' responsibility: one has long been responsible for the health and illness of the body, but now one must also know and manage the implications of one's own genome. The responsibility for the self to manage its present in the light of a knowledge of its own future can be termed 'genetic prudence' (c.f. O'Malley 1996). Such a prudential norm introduces new distinctions between good and bad subjects of ethical choice and biological susceptibility. This contemporary biological citizenship operates within what we term a 'political economy of hope.' Biology is no longer blind destiny, or even foreseen but implacable fate. It is knowable, mutable, improvable, eminently manipulable. Of course, the other side of hope is undoubtedly anxiety, fear, even dread at what one's biological future, or that of those one cares for, might hold. But whilst this may engender despair or fortitude, it frequently also generates a moral economy of hope,

in which ignorance, resignation and hopelessness in the face of the future is deprecated. This is simultaneously an economy in the more traditional sense, for the hope for the innovation that will treat or cure stimulates the circuits of investment and the creation of biovalue.

Biological citizenship also has a collectivising moment. As Paul Rabinow has shown, new forms of 'biosociality' and new ethical technologies are being assembled around the proliferating categories of corporeal vulnerability, somatic suffering, and genetic risk and susceptibility (Rabinow 1996). Biosocial groupings – collectivities formed around a biological conception of a shared identity – have a long history, and medical activism by those who refuse the status of mere 'patients' long predates recent developments in biomedicine and genomics. Many of these earlier activist groupings were fiercely opposed to the powers and claims of medical expertise. Some remain implacably anti-medical; others operate in a manner which, whilst not explicitly 'opposed' to established medical knowledge, prefers to remain 'complementary' to it. Nonetheless, we suggest, collectivities organized around specific biomedical classifications are increasingly significant. The forms of citizenship entailed here often involve quite specialised scientific and medical knowledge of one's condition: we might term this 'informational bio-citizenship.' They involve the usual forms of activism such as campaigning for better treatment, ending stigma, gaining access to services and the like: we might term this 'rights bio-citizenship.' But they also involve new ways of making citizenship by incorporation into communities linked electronically by email lists and websites: we might term this 'digital bio-citizenship.'

Thus, as Heath, Rapp and Taussig (2002) have pointed out, citizenship in the contemporary age of biomedicine is manifested in a range of struggles over individual identities, forms of collectivisation, demands for recognition, access to knowledge and claims to expertise. It is creating new spaces of public dispute about the minutiae of bodily experiences and their ethical implications - a politics of embodied or somatic individuals. It is generating new objects of contestation, not least those concerning the respective powers and responsibilities of public bodies, private corporations, health providers and insurers and individuals themselves. It is creating novel forums for political debate, new questions for democracy and new styles of activism. In each case, the forms that these are taking are shaped by many factors that vary in different national contexts, notably their differing biopolitical histories and modes of government, their traditions of activism and their presuppositions about persons and their rights and obligations. In the remainder of this paper, we explore these issues in relation to some empirical examples from a number of different configurations: bipolar affective disorder, Huntington's Disease and PXE. Our aim is largely descriptive – to begin to map the new territory of biological citizenship and to develop some conceptual tools for its analysis.

Making up the nation

Paul Gilroy has suggested that gene-oriented constructions of 'race' are very different from 'the older versions of race-thinking that were produced in the eighteenth and nineteenth century.' As the relations between human beings and nature are transformed by genomics, the meaning of racial difference is changed and this provides the possibility of challenging the tainted logic of raciology (Gilroy 2000: 15). His assessment may be optimistic, but it points to the way in which certain

presuppositions about biology bound together thinking about nation, people, race, population and territory from the eighteenth century onwards. To think of individual and collective subjects of European nations was to think in terms of blood, stock, physiognomy, inbuilt moral capacities. Those over whom Europeans would exercise colonial dominion were also thought of in these terms. In short, citizenship was grounded on what, from the early nineteenth century onwards, would be termed 'biology'. Distinctions within nations as to those more or less worthy of, or capable of, citizenship, and distinctions between peoples, as to their respective capacities to rule and be ruled, were built on an explicit or implicit biological taxonomy inscribed in the soma of both individual and collective and passed down through a lineage.

This is not the place to review the various ways in which people, race, nation, history and spirit were linked in the blood, divided and placed into hierarchies and patterns of descent. These can be traced from the philosophers of eighteenth century liberalism, such as Locke and Mill, through eighteenth and nineteenth century raciology, into the political debates about racial deterioration and degeneracy in the second half of the nineteenth century, and concerns about the consequences of the size and fitness of the population for the fate of nation states in imperial rivalry. Ideas of character and constitution, of blood, race and nation, remained inextricably intertwined in the eugenic arguments of the first half of the twentieth century, which shaped the political imagination of the nation states of North America, the Nordic countries, Australasia, South America, and elsewhere. Such ideas were translated into many different strategies to preserve the biological make up of the populations of states. Some focused on outside threats, such as those posed by immigration from lower races. Others focussed on threats from within, such as the dangers posed by the breeding of

defective, insane, sick or criminal individuals and their kin. Conceptions of the biological basis of national identity and national unity underlay many legal definitions of nationhood and citizenship in terms of descent. In Germany the citizenship law of 1913 which was framed in these terms and defined citizenship in terms of the line of descent, survived the Nazi experience and remained in force until 1999.³ In the 1920s, Chinese citizenship was built on a myth of a single lineage of blood of the yellow race (Dikötter 1998). In the same period in Mexico, some attempted to argue that it was the fusion of blood that gave the Mexican race its defining characteristics (Leys Stepan, 1991). The nation was not only a political entity, it was a biological one. It could be strengthened only by attention to the individual and collective biological bodies of those who constituted it.

Within these twentieth century projects of biological citizenship, there were clear differences between those who felt that their objectives could only be reached by strategies involving compulsion and those who opposed compulsion in the name of liberty. But this distinction did not map onto a simple division between strategies of reproductive control and strategies of health education and public health. Emphasis on the need to educate individuals so that they will take personal responsibility for the genetic implications of their reproductive decisions is not new: the genetic education of the citizen was a constant theme in the eugenic period. Early eugenicists developed all sorts of events to encourage individuals and families to reflect on themselves, their marriage partners, and their past and future lineage in eugenic terms, with a view to enhancing healthy procreation. Through education, the genetic citizen was to be enabled to take responsibility for his or her own heredity. We shall return to this question presently.

What, then, of the present? It would be too simple to believe that such concerns with the biological and/or genetic make-up of the population and the individual citizen have ceased to be matters of national political concern. The very existence of state supported public health measures indicates that the vital biological existence of the citizen remains an issue within the political rationalities of the present. The very existence of certain practices that have now become routine in medical care - ultrasound, amniocentesis, chorionic villus sampling and more - shows that judgements of value concerning certain features of the bodies and capacities of citizens have become inescapable - even if it is the individual citizen and her family who must carry the responsibility for the choice now rendered calculable for them. And successive state funded health promotion programmes show how the biological education of the citizen remains a national priority, although it is now supplemented by a host of other forces seeking to shape the reflexive gaze through which the citizen views his or her past, present and future biological corporeality.

And, from another perspective, national genetic peculiarities became a key resource for genetics over this period. This involved the search for lineages with a high incidence of particular diseases and the belief that the study of such pedigrees would provide the key to unravelling the genetics of disease. We can take Finland as our initial example (see Bergelund 2002). It has long been recognised by geneticists that sectors of the Finnish population are attractive for gene hunting because of a combination of low geographical mobility, relatively high rates of 'inbreeding', good genealogical and health records, and high rates of prevalence of certain diseases. For example, many claims about the discovery of genes linked with schizophrenia, manic

depression, alcoholism and other disorders were based on genetic research in Finland. In the age of genomics, such conditions which were once seen as burdens on the national population and its health service, have become potentially valuable resources: hence, they are included in the Finnish proclamation of biotechnology as a national imperative. As we discuss in detail later, the national population has become a resource not only for understanding particular pathologies, but also for profitable biomedical exploitation.

Making biological citizens: from public value to *biovalue*

Over the past decade, campaigns of popular education have been undertaken in the belief that it is crucial to increase the ability of citizens to understand the complex ethical and democratic dilemmas brought about by scientific and technological progress. Increasing the ‘public understanding of science’ is seen as a means of regaining the confidence and trust of lay members of the public in the regulatory mechanisms that govern science, and in biomedical expertise more generally. It is additionally seen as a mechanism for redressing a kind of ‘democratic deficit’ that is said to exist when citizens do not actively participate in shaping scientific and technological futures. Such arguments concerning the need to enhance the scientific – in this case, the biological – understanding of citizens have a long history. We have already commented on the attempts by eugenicists and similarly minded educators in the 1920s and 1930s to inculcate a particular version of scientific literacy – in this case the capacity to reflect in a eugenically informed manner on reproductive and marital choices. These attempts were one of a number of ways in which the capacities of the individual for citizenship have been linked to his or her understanding of ‘advances in science’.⁴

We can view such endeavours to educate the public about science and technology as aspects of strategies for ‘making up’ the biological citizen.⁵ By ‘making up citizens’, we mean, in part, the reshaping of the way in which persons are understood by authorities – be they political authorities, medical personnel, legal and penal professionals, potential employers or insurance companies – in terms of categories such as the chronically sick, the disabled, the blind, the deaf, the child abuser, the psychopath. These categories organise the diagnostic, forensic and interpretive gaze of different groups of professionals and experts. Classification of this sort is both ‘dividing’ and ‘unifying.’ It delimits the boundaries of those who get treated in a certain way – in punishment, therapy, employment, security, benefit or reward. And it unifies those within the category, over-riding their specific differences. Here, we can point to the way in which new biological and biomedical languages are beginning to ‘make up citizens’ in new ways in the deliberations, calculations and strategies of experts and authorities: for example the emergence of categories such as the child with attention deficit hyperactivity disorder, the woman with pre-menstrual dysphoric disorder, or the person who is pre-symptomatically ill because of genetic susceptibilities.

By making up biological citizens, we also mean, the creation of persons with a certain kind of relation to themselves. Such citizens use biologically coloured languages to describe aspects of themselves or their identities, and to articulate their feelings of unhappiness, ailments, or predicaments. For example, they describe themselves as having high levels of blood cholesterol, as vulnerable to stress, as being immunocompromised, or as having an hereditary predisposition to breast cancer or

schizophrenia. Such persons use those languages, and the types of calculation to which they are attached, to make judgements as to how they could or should act, the kinds of things they fear and the kind of lives for which they can hope. In part, of course, the languages that shape citizens self-understandings and self-techniques are disseminated through authoritative channels – health education, medical advice, books written by doctors about particular conditions, documentaries on television that chart individuals coping with particular conditions. Whatever may be said about their general level of scientific literacy, in these areas, individuals are actively engaging with biological explanations and are forming novel relations with figures of scientific or medical authority in the process of caring for, and about, health. But the contemporary biological citizen sits at the intersection between these more or less authoritative endeavours and a variety of other flows of information and forms of intervention. Or perhaps, ‘sits’ is the wrong term – for even while sitting, an active scientific citizenship is increasingly enacted, in which individuals themselves are taking a dynamic role in enhancing their own scientific – especially biomedical – literacy. They are doing this using a variety of media, but most notably through linking up with support groups - often now through the use of the Internet. The active search for scientific knowledge is particularly marked in the field with which we are concerned – that of health and illness, of medicine, genetics and pharmacology – in what Rabinow (1994) has termed ‘the third culture’, where an individual’s own vitality is at stake, or that of those for whom they care. In engaging with such issues, the language with which citizens are coming to understand and describe themselves is increasingly biological.

For those suffering directly or indirectly from illness or disability, reading and immersing oneself in the scientific literature of the illness that oneself or a loved one suffers from can be a key technique. This knowledge can be used to gain a better understanding of the disease process, to provide better levels of care to those suffering from an illness, and to discuss and negotiate with the doctor a range of therapeutic possibilities. Over the last decade, the Internet has come to provide a powerful new way in which those who have access to it, and who are curious about their health or illness, can engage in this process of biomedical self-shaping. But a key feature of the Internet is that it does not only give access to material disseminated by professionals, it also links an individual to self-narratives written by patients or carers. These accounts usually offer a different narrative of life with an illness, setting out practical ways of managing a body that is ill, the effect and harms of particular therapeutic regimes, ways of negotiating access to the health care system and so forth. That is to say, these narratives provide techniques for the leading of a life in the face of illness. They have a further distinctive feature, which relates to truth itself. Strategies for making up biological citizens ‘from above’ tend to represent the science itself as unproblematic: they problematize the ways in which citizens misunderstand it. But these vectors ‘from below’ pluralize biological and biomedical truth, introduce doubt and controversy, and re-locate science in the fields of experience, politics and capitalism (cf. Claeson, et al. 1996).

In response to the perceived power of such problematizations from below, those whose investment in biomedicine is measured in terms of capital returns and shareholder value – the biotech, biomedicine and pharmaceutical companies – now actively engage in these processes of self-education of active biological citizens.

They set up and sponsor many of the consumer support groups that have sprung up around disorders from attention deficit hyperactivity disorder (ADHD) to epidermolysis bullosa (EB) In doing so, they seek to represent their activities and their products as beneficial, to counter the claims of the critics, and to educate actual or potential consumers of their products. In the United States, recent legal changes allow pharmaceutical companies to engage in ‘direct to consumer advertising’ and television advertisements for the benefits of different brands of psychiatric drug are now widespread. But, across all jurisdictions, such companies are now using of the Internet for this purpose. It is thus worth considering one example from this domain in some detail.

The Prozac website maintained by Eli Lilly is emblematic of techniques to promote a particular version of scientific or biological literacy (www.prozac.com). The home page of this site is titled “Your Guide to Evaluating and Recovering from Depression”. Prozac.com thus represents itself as a resource centre where individuals can learn more about depression, its treatments and ways to securing a recovery. It claims – characteristic of all such ‘direct to consumer’ practices – that the information and knowledge provided on this website is not intended to supplant the authority of the health professional, but rather to encourage the person suffering from depression to form an “active” alliance with the medic in the realisation of a programme of care. But, of course, this activity is to take a specific, brand related, form: a form supported through the provision of information on how Prozac can aid in recovery from depression.

In part, this is a matter of forming the problem in a particular manner. The Prozac.com website uses a biological explanation of depression, couched in terms of the action of neurotransmitters. Text and animated images are used to provide a way for individuals to understand their depression at a molecular level, in terms of chemical imbalances and the action of neurotransmitters, and to imagine the ways in which Prozac can directly target and correct these molecular imbalances. It is, it seems, important to learn about the action of Prozac. This is not because taking the drug is all that is required of the individual. On the contrary, it is because the individual should know “what to expect while you work toward your recovery” (http://www.prozac.com/How_ProzacCanHelp.jsp) The process of recovering from depression does not simply require compliance with a drug regime: “You can and should be an active participant in your recovery from depression” (www.prozac.com/DiseaseInformation/Recovery.jsp). This process of recovery enlists a whole range of techniques of the self: practising self-discovery, liking yourself, being kind to oneself, reducing stress, engaging in physical exercise, eating well, writing lists and keeping diaries, building self-esteem, joining a support group, or reading the Prozac.com newsletter. This website is thus an element in what we term ‘the political economy of hope’ (of which more later) in that it sutures together hopeful beliefs that one can recover from depression if one knows how to recognise and deal with it and the marketing of the drug Prozac itself.

The role of biomedical authority here is not to encourage the passive and compliant patient-hood of a previous form of medical citizenship. Citizenship, here as elsewhere, is to be active. Thus the actual or potential patient must try to understand their depression, to work with their doctor to obtain the best programme of medical

care, to engage in self-techniques to speed the process of recovery – and, of course, to ask his or her doctor to prescribe Prozac by name. Indeed, as the daily form of Prozac is now out of patent, the website seeks to maintain market share. On every single web page, a banner advertises a free trial of Prozac® Weekly™ - which is in patent - and tells patients that they can ask their doctor about this new formulation. Another page suggests that there may be differences between brand name Prozac and its generic equivalent, fluoxetine hydrochloride, explaining to potential customers that there is no such thing as ‘generic Prozac’ – for example they come in different packaging - and that if they feel uncomfortable about changing to a generic, they should ask their doctor to prescribe brand name Prozac (www.prozac.com/generic_info.jsp). What kind of scientific literacy is being promoted here? What kinds of active biological citizens are being shaped, and to what ends? This is the citizenship of brand culture, where trust in brands appears capable of supplanting trust in neutral scientific expertise. The weaving together of Eli Lilly’s commitment to education and brand marketing gives us the title of this section of our paper – from public value to biovalue – for this is just one example of the way in which biovalue is supplanting public value in the biological education of citizens-consumers.

Biosociality: active biological citizens

Perhaps we have given the impression that biological citizens are individualized, required to understand their nature and cope with their fate alone or with their own family, accompanied only by the ministrations and advice of experts, the solitary reading of informative material, or seated alone at their computer searching the Web. Undoubtedly such isolation is the condition of many. But it is not the destiny of the biological citizen to be an isolated atom, at least in circumstances where the forms of

life, ethical assumptions, types of politics and communication technology make new forms of collectivism possible. Perhaps the templates for these new forms of biological and biomedical activism were the campaigning groups that arose around AIDS, especially in the English speaking world. AIDS activists organised themselves into groups, and through a variety of means constituted those who were actual or potential sufferers from the condition as 'communities' for which they would speak and to which they were responsible. These groups had a number of functions: to spread information about the condition; to campaign for rights and combat stigma; to support those affected by the illness; to develop a set of techniques for the everyday management of the condition; to seek alternative forms of treatment; and to demand their own say in the development and deployment of medical expertise.

The case of HIV and AIDS activism is exemplary for another reason: whilst initially relations between the activists and the conventional biomedical community were antagonistic, gradually an alliance developed. For the community, and the identifications it fostered, came to provide key elements for the government of HIV and AIDS. That is to say, it was through their identification as members of this community, that those in 'high risk groups' were recruited to their responsibilities as biological citizens, and health educators came to realise that it was only by means of the translation mechanism provided by AIDS activists that they would be able to gain the allegiance of the active gay men who were their primary target. In allying itself with the health establishment in promoting the message of safe(r) sex, AIDS activists, in return, would have their say in the organisation and deployment of social resources, and indeed gain the resources necessary for their activities. This was not a matter of co-option, although some saw it as such, but of alliances and translations. And

'governing through community' produced its own problems. Most notably, that of shaping the conduct of a younger generation of gay men who did not identify themselves in the same terms as the previous generation, and that of governing the conduct of 'men who had sex with men' but who did not identify themselves as part of any gay community.

Since the 1980s, biosocial communities following a roughly similar form have proliferated, and, since the advent of the World Wide Web, they have found the Internet a congenial host territory. Take, for example, the issue of manic depression. Until quite recently in the UK at least, in addition to physicians and medics, those with such a diagnosis or their families (if they were not amongst the very few actively allied to the anti-psychiatry movement) could access only one other organised source of information and support: the National Association for Mental Health (MIND). Things began to change in the 1980s. In 1983, the Manic Depression Fellowship was founded, which described itself as a 'user led' organisation whose aims are to "enable people affected by manic depression (bi-polar) to take control of their lives" through the services this organisation offers (<http://www.mdf.org.uk/about/>). These services include: MDF self help groups, information and publications, employment advice, the MDF Self Management Training Programme, a 24-hour Legal Advice Line for employment, legal, benefits and debt issues, a travel insurance scheme". MDF also seeks to combat the stigma and prejudice experienced by those affected by manic depression, raise awareness of the disease, and develop partnerships with other organisations concerned with mental health (<http://www.mdf.org.uk/about/>).

Over the 1980s, the MDF was joined by a host of other user and survivor led organisations, some local and some national. And twenty years later, these sources of biosociality have proliferated, especially on the World Wide Web. True that those based the UK are somewhat few and far between. But outside the UK the resources are manifold. For example, Pendulum Resources, is a website that presents itself as a “Bipolar Disorders Portal” a gateway to comprehensive quasi-medical and other information. It urges people with bipolar disorder to participate in the NIMH-funded Bipolar Genome Study at the Washington University School of Medicine and in other similar projects in the hope that “this kind of study will enable medical researchers to find safer, more effective treatments for Mental Illness and brain disorders” (<http://www.pendulum.org/>). Pendulum also provides links to at least 24 homepages of people diagnosed with, or living with bipolar disorder who describe, in very different ways, their modes of living with the condition. These include, for example, “A Better Place to Be” (<http://www.searchingwithin.com/bipolar/>) which contains, amongst other things, a diary of the website’s author’s “personal struggle with bipolar disorder”, a journal and a link that enables readers to ask questions.

These new forms of citizenship are not always premised on genetics. Many of these biosocial communities do indeed refer to genetics, but its significance varies. Whilst in single gene or single substitution disorders such as Huntington's, PXE or Canavan's disease, genetics clearly plays an organising role, in the biosociality forming around other conditions, genetics is not dominant. In the case of bipolar disorder, for example, visitors to the Pendulum website are urged, as we have mentioned, to consider participating in genomic research. In the case of “A Better Place To Be”, under the page entitled “Sources of My Depression” the author writes under the

heading of ‘serious reasons’: “a genetic heritage that comes from being half Finnish” and “other genes in my DNA that tend toward improper chemical balance” but also cites her “need for more vocational satisfaction and personal fulfilment” her “lack of recovery from a dysfunctional childhood” and what she terms “whiney reasons” such as “nobody loves me”, “everyone hates me”, “tendency at times to identify any negative feeling as depression”, and “lack of disposable income to purchase all the fun and necessary things I must have!” (<http://www.searchingwithin.com/bipolar/notes/reasons.html>).⁶ What can be learned of biosociality from such sites?

Rayna Rapp (1999), writing about women and men facing complex reproductive decisions brought about by the technology of amniocentesis, designates them as ‘moral pioneers’. Her argument - which would include AIDS activists (Martin 1994, Epstein 1996) - captures something crucial. These women and men are pioneers because, in their relation with their bodies, with their choices, with experts, with others in analogous situations, and with their destiny, they must shape new ways of understanding, judging and acting on themselves, and must also engage in a kind of re-imagining of those to whom they owe responsibilities – their progeny, their kin, their medical helpers, their co-citizens, their community, their society. We think, in an comparable way, the new biosocial communities forming on the Web and outside it are moral pioneers - we would prefer to say ‘ethical pioneers’ - of a new kind of active biomedical citizenship. They are pioneering of a new informed ethics of the self – a set of techniques for managing everyday life in relation to a condition, and in relation to expert knowledge. Whilst some might deride these techniques of the biomedical self as a kind of narcissistic self-absorption, we think that they show an admirable ethical seriousness. Like those techniques Foucault (1985; 1986) found

amongst the Greeks, they identify an aspect of the person to be worked upon, they problematize that field or territory in certain ways, they elaborate a set of techniques for managing it, and they set out certain objectives or forms of life to be aimed for.

Of course, in a certain political, cultural and moral milieu, this idea of activism in relation to one's biomedical condition becomes a norm. Activism and responsibility have now become not only desirable but virtually obligatory – part of the obligation of the active biological citizen, to live his or her life through acts of calculation and choice. Such a citizen is obliged to inform him or herself not only about current illness, but also about susceptibilities and predispositions. Once so informed such an active biological citizen is obliged to take appropriate steps, such as adjusting diet, lifestyle and habits in the name of the minimisation of illness and the maximisation of health. And he or she is obliged to conduct life responsibly in relation to others, to modulate decisions about jobs, marriage, reproduction in the light of a knowledge of their present and future biomedical make-up. The enactment of such responsible behaviours has become routine and expected, built in to public health measures, producing new types of problematic persons – those who refuse to identify themselves with this responsible community of biological citizens (cf. Callon and Rabearisoa 2000).

Of course, these obligations, and the forms of biosociality with which they are linked, are specific to certain times and spaces. Despite the much vaunted global span of the Internet, Manuel Castells (1996) has documented the national and regional variations in access to the Internet, which is dependent on the availability of telephone lines and other basic communication technology, as well as the penetration of the computer

hardware and software necessary to access it. Whilst young travellers of the world may be able to dial up their Internet connection from almost anywhere, the same is hardly true of those who are the prime potential subjects of biosociality. The kinds of biosociality we have documented in the United States, Europe and Australia are not merely a product of the availability of certain technological means of communication, but of conceptions of citizenship and personhood. In particular, they connect up, in various ways, with the history of previous forms of activism in the feminist, gay and AIDS movements, with the varieties of identity politics and the existence of a vociferous politics of rights and recompense. Hence the forms of biosociality that we have documented have no visible presence in whole geographical regions. AIDS biosociality in sub-Saharan Africa is very different from that of Paris, San Francisco or London (Nguyen 2002). Biological citizenship in Ukraine is not a matter of contesting the power of medical expertise, nor of sculpting an autonomous life in which collectively shaped self-understandings are a pathway to self-fulfilment: it takes the form of demanding redress from the state for certain ills, in the form of benefits, and activism is oriented towards demanding medical recognition for a condition and obtaining expert judgement as a credential to obtain state benefit (Petryna 2002).

Political economies of hope: science, citizenship and the future

Citizenship has long associations with forms of local political activism: involvement with the local work of political parties, working in charitable organisations, and for causes such as reducing inner city poverty or improving literacy, as well as small scale activities such as charity bake sales, car washes or raffles in order to support the local church, school or community centre. These aspects of citizenship are constantly

reshaped in relation to new causes and are often inventive in their styles of organizing and activism. We have already discussed the ways in which, since the 1980s, there has been an upsurge in citizen activism and political inventiveness around issues of health and illness. But while patient's organisations and support groups have been around for many years, today we see one notable innovation: the formation of direct alliances with scientists. Patients organisations increasingly are not content with merely raising funds for biomedical research but are seeking an active role in shaping the direction of science in the hope that they can speed the process by which cures or treatments are developed. Recent discoveries in the fields of genetics and the neurosciences have given rise to the hope that cures and treatments for many human diseases will be found in the near future. This has intensified a particular form of the capitalisation of life and its investment with significant social meaning that we have termed 'a political economy of hope' (Novas 2001). This phrase tries to capture the forms of political activism and fundraising by citizens themselves and the patients' groups which represent them as they seek to act upon the world of science. It also tries to encapsulate the ways in which life itself is increasingly locked into an economy for the generation of wealth, the production of health and vitality, the creation of social norms and values. Contemporary biological citizenship, that is to say, is a hopeful domain of activity, one that depends upon and intensifies the hope that the science of the present will bring about cures or treatments in the near future.

This economy of hope is not eschatological, rather it comprises a domain of possibility, anticipation and expectation that requires action and awareness of the present in order to realise a range of potential futures. Hope, as it is manifested in contemporary patients' organisations, is not passive: it rather requires an active stance

towards the future, and involves a certain degree of commitment, in addition to a willingness to take chances in order to bring about the outcomes that are individually and collectively hoped for. Hope thus ties together personal biographies, the aspirations that patients share for better treatments or a cure, and the campaigns of patients' groups to achieve particular goals. Lastly, of course, this political economy of hope often takes place under conditions of suffering, privation and inequity: it is contoured by the shortcomings of the social security system, the lost earnings and personal difficulties of having to care for a loved one, the lack of funding for scientific research on rare diseases, and the discrimination meted out by insurance companies and employers to those affected by a range of human illnesses.

Within this political economy of hope, a key role is often played by the personal advocacy efforts of creative individuals. Carmen Leal is one such person. Her ex-husband Dave suffers from Huntington's disease and she is still actively involved in his care. She also plays an important role in providing support to other carers through an online mailing list called Hunt-Dis.⁷ Carmen Leal also advocates on behalf of those with the disease through such activities as editing a collection of stories and poems about persons experiences with the disease (Leal-Pock 1998), using her speaking and singing skills to provide inspiration to others,⁸ and maintaining a website alongside others called the Huntington's Disease Advocacy Center.⁹ In an article published on this website entitled "The Last Generation", Carmen refers to how "various members of the HD family point out the desire for this to be the last generation to have to worry about Huntington's Disease. Thanks to researchers, there is now tremendous hope that this will definitely be the last generation" (2000). However, she does not believe that it is the exclusive task of scientists to find a cure

for the disease: she asks “So what can you do in this fight?” (2000). Her 10 point list of the ways that individuals can personally contribute to this endeavour serves as a useful starting point to examine the forms of citizen activism and ethical self-formation that are constitutive of a political economy of hope.

Carmen’s 10 point programme includes the suggestion that persons educate themselves and read about various aspects of disease – the Internet providing a useful starting point for this education and literacy project. She urges individuals to express themselves with whatever talents they possess and to communicate with others, a process which may have therapeutic effects upon themselves and possibly help others in a similar situation. She highlights the importance of saving and giving: Carmen suggests that “We all have spendable income that we can squirrel away and donate for the cure”. In very practical terms, Carmen asks “Do you drink at least one soda from a machine every day? A seventy-five cents a can, that’s \$273.75 a year for the cure” (2000). She suggests that visitors to the website participate in fundraisers which not only contributes to the cure, but also help to raise awareness of the disease. In this political economy of hope, citizenship is enacted through ethical self-formation, through personal economising, and through activism. It thus tries to constitute a public arena in which responsibility for the cure is not merely attributed to scientists and doctors, but is embraced by those who have a stake in the suffering wrought by a disease such as Huntington’s. Hence this exemplifies the formation of new public arenas in which the hopes and responsibilities of citizens become tied more closely to their biology.

We can explore these links between the hopes of citizens and their biology a little further by pursuing the example of the Huntington's Disease Advocacy Center website. The right hand frame of this site contains links to a whole range of scientific articles written on Huntington's disease. Biological citizens, that is to say, are encouraged to read and to understand their condition in particular, and their biological existence in general in the languages and rhetorics of contemporary bioscience and biomedicine. Citizenship takes on new biological colourations and hope becomes bound up with scientific truth. Marsha L. Miller Ph.D., one of the contributing editors of the Huntington's Disease Advocacy Center, in an article entitled "Reasons for Hope" illustrates how the advances made in understanding Huntington's disease provide a rationale to look towards the future with expectation (Miller 2000). One reason why individuals affected by this disease should be hopeful can be found in the "exceptionally dedicated researchers" whose willingness to collaborate, share ideas, and collegiality has "undoubtedly shortened the time to the cure" (2000). A second reason for hope is that researchers have discovered that a number of other neurodegenerative diseases are caused by excessive polyglutamine repeats, and that research in these other diseases, may aid in the quest to find a cure for Huntington's. A third reason consists of the creation of transgenic HD mice which not only opens pathways to understanding the pathogenic process, but provides an experimental site in which to test potential therapies. The seed money provided by the Hereditary Disease Foundation and the Huntington's Disease Society of America constitutes a fourth reason for hope as they play a "critical role in funding more speculative studies that might not get funded if the researchers had to compete for funds with researchers addressing a spectrum of diseases" (2000). Thus we can see that bioscience is not only about the production of truth: it can become invested with hope and optimism by

citizens who have an active stake in their health and that of others. In such a political economy of hope, this investment in bioscience by patients and patients' organisations is made through directing energy to political activism, donating parts of ones' earnings, gifting blood and tissues samples, providing care to others, and participating in clinical trials. These forms of political activism and biosociality created through the experience and suffering wrought by a disease such as Huntington's potentially at least extend beyond it to shape the field occupied by other diseases and those who suffer from them and research into them.

Biological citizenship in a political economy of hope requires active political engagement – it is a matter of *becoming* political. A certain amount of education and technical administration is required in order to make ones' individual and collective voice heard. The Political Activist section of the Huntington's Disease Advocacy Center website provides a range of tips on how to make biological citizenship effective. Using hypertext links, this section provides information on how to lobby elected officials, how to prepare for a meeting with a political representative, how to build coalitions, a list of who to contact, and samples of correspondence written to political officials. One topic of concern to members of this coalition and other patients' groups in 2001, was President George W. Bush's ban on stem cell cloning. Stem cell research is thought to provide a promising avenue for research on Huntington's disease, in addition to a number of other neurological disorders. As such, it provides opportunities for coalition building with other patients' organisations. The policy related sections of patient's groups websites show an active engagement with the new terms of inclusion of life itself into the body politic. Politics, as it is enacted by biological citizens in a political economy of hope involves

profoundly normative judgments about values and ethics concerning the uses and ends of life itself.

Producing *biovalue*: materializing ethics, health and wealth

As politics begins to take on more ‘vital’ qualities, and as life itself becomes invested with both social meaning and capital, the vitality of each and all of us becomes a potential source of *biovalue*. The bodies and vitality of individual and collective subjects have long had a value that is as much economic as political – or rather, that is both economic and political. As for citizenship itself, however, from the nineteenth century onwards, the preservation of this value and its enhancement became a matter of state: political authorities took on the obligation and responsibility for preserving, safeguarding and enhancing the biological capital of their population. Along this dimension we can place a whole sequence of developments from clean water and sewage, registration of births and deaths, child welfare and maternity services, medical inspection of schoolchildren, and indeed the development of state organised national health services. Of course, private enterprises played a key role, in producing the food, services and pharmaceuticals that would simultaneously generate private profit and public good. A market economy of health came into being. Over the twentieth century, this market was increasingly shaped by the activities of the ‘social’ state – regulating purity and hygiene of foodstuffs and the production and marketing of pharmaceuticals. But the regulated political economy of health – consisting of relations between the state apparatus, scientific and medical knowledge, the activities of commercial enterprises and the health related consumption of individuals – is being reshaped.

Recent advances in the fields of genetics and the neurosciences, transform the potentialities embodied in life itself into a source of value creation. We have used the term biovalue for this – a term introduced by Catherine Waldby in her study of the Visible Human Project (Waldby 2000, see also Waldby 2002; for analogous concepts see Franklin 2002; Nguyen 2002). For Waldby, biovalue refers to the ways that the bodies and tissues derived from the dead are redeployed for the preservation and enhancement of the health and vitality of the living. We suggest that one can analyse three dimensions of biovalue. Along the first, we see how life is productive of economic value. Along the second, we see that the manipulation of life generates a value accorded to the enhancement of health. Along the third, we see that the production of both wealth and health is bound up with ethical values.

Let us begin with the consideration of biovalue and the creation of wealth.

Contemporary biomedicine, by rendering the depths of the body visible, intelligible, calculable and capable of intervention at a molecular level, makes it amenable to the production of economic value. In many ways, what is being accomplished through the life sciences is a kind of ‘flattening’ of the vital processes of the body. This not only enables these ‘surfaces’ to become equivalent with one another at the most basic biological level, but also allows them to be enfolded within processes of capital or social accumulation. They contain the potential to transform the vitality of each and all of us into a standing reserve for the creation of biovalue. One area where this is occurring draws on the health technologies of social citizenship and redeploys them in the service of biovalue. Two examples of this logic can be found in Sweden and Iceland.

A recent article in *Science* begins with the memorable lines: “Sweden and some other Nordic countries are sitting on a genomic gold mine. Their long-standing public health care systems have been quietly stockpiling unique collections of human tissue, some going back for decades... The samples were originally stored for possible therapeutic or diagnostic uses for the patients themselves, but researchers now realize that they could contain valuable information about inherited traits that may make people susceptible to a variety of diseases” (Nilsson and Rose 1999: 894). In many Nordic countries, census data, patient records and tissues samples maintained in the process of providing health care in the past – through a heritage which runs from the pastoral government of the Church, through that of the strong state to that of the social state – have been combined with large scale genomic analysis in order to transform their citizenry into a resource for the production wealth and health (for an account of developments in Iceland see Rabinow and Pálsson 2002). Thus, in Iceland, deCode genetics who were given an exclusive licence to create and operate such a database by an Act of the Icelandic parliament in 1998, declares in their mission statement that they are “Making the Map of Life... a Blueprint for Health”.¹⁰ The Swedish firm UmanGenomics, describes the “unique resources” that are available to it, including a “unique collection of blood samples and data in the Medical Biobank of Umeå” derived from records of health examinations of the local population amalgamated in an 1985 epidemiological study of the population combined with samples from state-supported medical examination and blood donation (Høyer 2002a; 2002b).¹¹ Despite the origins of these samples in public health, “UmanGenomics has the exclusive rights to commercialise information derived from these samples.”¹² In these and other cases, then, the state plays an active role in transforming their citizens into a potential resource for the generation of wealth and health.

However, this transformation need not come from above – the state and private enterprise. It can also come from below, from patients' organisations themselves. Take the example of a patients' organisation called PXE International. This group was founded by Patrick and Sharon Terry in 1995, after their two kids, Elizabeth and Ian, were diagnosed with pseudoxanthoma elasticum (PXE). They played an important role in forming networks of support amongst affected families, getting researchers interested in studying the disease, organising conferences for scientists and patients, and lobbying the U.S. government for more funding to be directed towards the study of PXE, but also of skin diseases more generally. PXE International also established a blood and tissue registry in order to create a central repository, and to avoid the need for patients suffering from the disease to donate multiple samples. By maintaining this registry PXE International is able to exert an influence on how this material is used and also a share of intellectual property rights that arise from it.

The productivity of this blood and tissue registry for the generation of biovalue was demonstrated in 1997, when the gene for PXE was discovered by researchers at the University of Hawaii. This discovery not only generated new insights into the pathology of the disease, but also the potential for property rights. The technology transfer unit at University of Hawaii was initially reluctant to yield patent rights to PXE International, but as they had previously negotiated the terms and conditions of access to the registry, in addition to Sharon Terry being named as a co-inventor, they were able to work out a process of sharing royalties with the University and a stake in deciding on licensing deals: from their perspective, this is a vehicle for ensuring that any resulting medical treatments be affordable and accessible (Fleischer 2001). As

can be seen, the ownership of this gene by PXE International is not driven by a logic of commercialisation, but rather to serve the values and interests of persons suffering from genetic diseases. Patrick Terry defends the potential of patient controlled patents, asserting that “We’re not interested in lining our pockets. We just want a cure” (quoted in Coghlan 2001).

A further dimension of contemporary biovalue can be seen in attempts to produce health and vitality from blood and tissues samples extracted from the living and the deceased. We will focus here on the ways in which knowledge of a single condition such as PXE can lead to the production of health and vitality for those affected by a particular disorder, but, potentially, for all of us. For the discovery of the genetic basis of PXE not only offers hope that a treatment may some day be available to those who suffer from this illness, but also holds out a promise to others who suffer from apparently unrelated disorders. It is suggested that the opening of this particular genetic pathway on chromosome 16 may shed light on hypertension and cardiovascular research, since the mineralization of the midsize arteries in PXE mimics the general ageing of the arteries (Fleischer 2001). PXE may also provide clues to macular degeneration; this affects the eyesight of many individuals suffering from this disorder, but another 60 million Americans are thought to be at risk for this condition due to ordinary ageing (Fleischer 2001). As PXE International owns a share of the patent for the gene, they have the potential to gain significantly if a broader use for the gene is found. However, Sharon Terry says that PXE International will resist the temptation of patient profiteering: she claims in an article in *The American Lawyer*, “It’s been suggested that we could make a killing because who cares if we’re making the cost of cardiovascular treatment huge. We always say, we don’t just

represent people with PXE, we represent anybody, who has anything” (quoted in Fleischer 2001).

The visualization of the body at the molecular level not only creates new possibilities for the generation of wealth, but also generates new ethical values that spill over into market interactions. For the co-production of health and wealth is a profoundly ethical endeavour. As the life itself of the citizenry is increasingly being penetrated by market relations and productive of wealth, the morality governing the very nature of economic exchange is being reconfigured. In an economy where the vitality of biological processes can be bought and sold, ethics becomes both a marketable commodity and a service industry in its own right. UmanGenomics in Sweden, for example, trades on the fact that all the blood samples contained in its collection are drawn on the principle of informed consent (Høyer 2002a; 2002b). It proclaims that “Correct ethical handling of human tissue and medical data is essential” and highlights how it has been “...internationally recognized for its ethical stance and procedures”.¹³ Ethics, in this instance, is not only a means of access to a valued resource is obtained, but is also a marketable asset that the firm can trade upon in establishing relationships with other enterprises (Rosell 1991).

The growing importance of ethics in the commerce of extracting value from life can be seen in a recent start-up biotechnology firm in Redwood City, California called Genomic Health. This firm is a good example of how ethics is becoming central to the production of health and wealth, as well as how citizens are being made up as consumers of the potential range of goods which genomics has to offer. Genomic Health’s wish to be seen as committed to consumer concerns was manifested in the

recruitment of Patrick Terry as the director of consumer advocacy, in addition to firm's goal of trying to develop affordable genetic technologies. In bringing affordable genomics to the consumer, the chief executive officer, Dr. Randy Scott insists that the future of the genomics industry rests on the "education, trust and support of the consumer" and that the uptake of these new products will only take place on "a foundation built on bioethics" – a foundation "critical to engaging consumers... whether for research, for medical treatment, or for business" (Scott 2001). Ethics, in this sense is both a means of increasing the commercial value of products and a means of satisfying the values necessary to gain the trust and confidence of the citizen-consumer.

The enterprising forces behind Genomic Health forces us once again to consider the relation between public value and biovalue – for the values embedded in new genomic artefacts are polyvalent (Rose 2002). The multifaceted nature of biovalue complicates the entry of genomics products into the world of consumer goods and services. As the huge amount of literature generated in the name of the public understanding of science suggests, the process of bringing science to citizens and consumers requires that they be educated and are enabled to trust those who seek to reduce their suffering and enhance their quality of life. The chief executive officer at Genomic Health intermixes public and private value through his suggestion that it is critical "for industry to begin to create an open public dialogue with all stakeholders in order to facilitate understanding and to build trust" (Scott 2001). This dialogue, he claims will be both difficult and complex, but "Our quest to cure disease and prolong life will ultimately lead to much deeper questions – the very definition of what it means to be human". At stake here is not merely how one should act in an age where

our biology is open to remediation and modification through the forces of the market: the process of generating biovalue transforms our conception of human life itself.

Conclusion

We have argued that, while citizenship has long had a biological dimension, a new kind of biological citizenship is taking shape in the age of rapid biological discovery, genomics, biotechnological fabrication and biomedicine. New subjectivities, new politics and new ethics are shaping today's biological citizens. As aspects of life once placed on the side of fate become subjects of deliberation and decision, a new space of hope and fear is being established around genetic and somatic individuality. In the nations of the West – Europe, Australia and the United States, this is not taking the form of fatalism and passivity, and nor are we seeing a revival of genetic or biological determinism. Whilst in the residual social states in the post-Soviet era, biological citizenship may focus on the demand for financial support from state authorities, in the West novel practices of biological choice are taking place within a 'regime of the self' as a prudent yet enterprising individual, actively shaping his or her life course through acts of choice. In this regime, a 'political economy of hope' is taking shape – both a moral economy and an economy in the more traditional sense, of a space involving the creation and circulation of (bio)value. We have tried to describe some of the new forms of 'biosociality' – patient groups – and new ethical technologies that are being assembled around genetic risk and susceptibility. The new biological values that are taking shape are simultaneously ethical and commercial: life is productive of economic value, the manipulation of life embodies and incites the increasing value accorded to health; and new ethical dilemmas and possibilities arise in the links between virtue, vitality and biovalue. Those who operate in these complex dilemmas,

whether they be medics, patients, support groups or entrepreneurs, are ethical pioneers. In tracing out, experimenting with and contesting the new relations between truth, power and commerce that traverse our living, suffering, mortal bodies and challenging their vital limits they are redefining what it means to be human today.

NOTES

- ¹ We have discovered that others have used this term, although with different resonances. In particular NR has learned a great deal from Adriana Petryna's *Biological Citizenship: Science and the Politics of Health after Chernobyl* (Princeton University Press, 2002) and thanks her for generously letting him see this in manuscript. We draw on her use of the term here, as will become clear, although we place her specific usages of it in a more general context. A web search picked up a paper by Chris Latiolais called "The Body Politic: Naturalizing Biological Citizenship and Philosophical Reservations," delivered at a University of Chicago Midwest Seminar, in March 1998 but the author tells us in an email that "I don't take the term seriously at all. The term 'biological citizenship' is patently oxymoronic, the conflation of theoretical, natural-scientific categories with the quite different practical, moral-political categories of elective allegiance. The "naturalizing" qualifier ambiguously hints at the requisite process that might span the gap between organism and political identity, and the thrust of my paper consists in (1) just mentioning that gender classification as a biological concept is extremely confused (particularly binary sex classifications) and, more importantly, (2) that such classifications are wholly irrelevant to legal standing."

The idea of genetic citizenship is more widely used (see Peterson and Bunton, 2002) and we have benefited in particular from the work of Deborah Heath, Reyna Rapp and Karen-Sue Taussig on this theme and than them for allowing us to see some of their work in draft (e.g. Heath, Rapp and Taussig, 2003). However, from our perspective, genetic citizenship is only one possible articulation of a longer, and more diverse, array of ways in which citizenship has been linked to or articulated in biological terms. Similarly others, e.g. Abraham, 2002, have sought to apply the distinction between passive and active citizenship to an analysis of various aspects of health provision: our analysis clearly shares something with the view that contemporary citizens are obliged to be 'active' but we find the simple distinction of passive and active, and its mapping onto different stages of late capitalism, rather too crude a device to capture the complexity of the forms of biological citizenship we are seeking to describe.

In addition we would like to acknowledge initial guidance from Chetan Bhatt of Goldsmiths College, University of London and Engin Isin of York University, Toronto, comments from participants at the Prague conference on Global Anthropology where this paper was first given, especially Aihwa Ong and Stephen Collier, and comments from participants in a CRICT Seminar at Brunel University in November 2002. Particular thanks are due to Amaya Carmen Novas, who introduced us to some very contemporary aspects of biological citizenship.

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- ² We will not discuss conceptions of citizenship, and projects of citizen building, in earlier periods. For this, see Engin Isin, *Being Political: Genealogies of citizenship*, Minneapolis: University of Minnesota Press, 2002.
- ³ Christian Joppke, 2000, *Mobilization of Culture and the Reform of Citizenship Law: Germany and the United States*, available at http://www.europanet.org/conference2000/papers/a-2_joppke1.doc.
- ⁴ Notably, of course, Lancelot Hogben's *Science for the Citizen* (1938)
- ⁵ Our use of this phrase, obviously, derives from the work of Ian Hacking, e.g. Hacking 2002.
- ⁶ These range from antique wooden boxes, through art supplies and computer hardware and software, to music CD's, a big house and a weekly maid.
- ⁷ Hunt-Dis is an electronic mailing list where persons affected by HD, those at risk, and carers can discuss any topic relating to Huntington's disease.
- ⁸ Carmen Leal also maintains a website called [writerspeaker.com](http://www.writerspeaker.com), which aims to help aspiring writers and speakers to learn how to use the Internet for research and bring their products to market. See <http://www.writerspeaker.com/>.
- ⁹ This coalition was formed on April 1 2000 and is designed to provide support for HD families by HD families, in addition to providing a range of information and answers to those affected by this disease. Source: <http://www.hdac.org/about.html>.
- ¹⁰ Source: <http://www.decode.com/>. The company website further states that "Iceland makes an ideal home for the company, as the Icelandic population is, genetically speaking, relatively homogeneous. The country has a sophisticated, high-quality healthcare system and extensive genealogical records. Through these, resources can be generated to identify genes associated with a multitude of diseases. Research based on this unique population provides distinctive insights into the pathogenesis of these diseases, and the depth and comprehensiveness of deCODE's genealogical database are unrivalled worldwide" (<http://www.decode.com/company/profile/>).
- ¹¹ Source: <http://www.umangenomics.com/index2.asp>. The recognition of the potential of the Medical Biobank of Umeå for the production of biovalue was made by the technology transfer unit at the University of Umeå called the Technology Bridge Foundation (Abbott 1999).
- ¹² Source: <http://www.umangenomics.com/index2.asp>
- ¹³ Source: <http://www.umangenomics.com/index2.asp>. Apart from gaining the informed consent of research participants, novel uses of the tissue and information stored UmanGenomics' database require approval from a regional ethics committee in addition to the Swedish Medical Research Council. Source: <http://www.umangenomics.com/index2.asp> committee.) Sune Rosell, temporary chairman of UmanGenomics, in an article in *Science*, states that the company created a unique model for the handling of

ethical issues: “There is control at the individual level through informed consent, at the social level through the regional ethics committee which screens all research proposals, and at the population level, since local politicians sit as non-voting members on the boards of both the company and the Medical Bank” (quoted in Abbott 1999). Klaus Høyer’s (2002b) ethnographic fieldworks indicates how many participants in UmanGenomics database do not actually read the informed consent sheet that is provided to them, tacitly consenting to participate in this study, and only engaging in the public arena of informed consent when confronted in the context of the anthropological interview.

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