

Editorial

Since the late 1970s, *empirical science studies* have developed into a key field of research at the intersection of science, technology and society. This field merges a repertoire of theories and methods stemming primarily from cultural anthropology, sociology, linguistics and history. Its main characteristic is the detailed analysis of scientific practices and epistemic cultures and how these become entangled with public discourses and everyday life. This focus tries to reveal specific, local configurations and their epistemological as well as social consequences. Beyond a mere deconstruction, science studies are constantly looking to engage with the fields in which they do their work. The goal of this book series is to offer to scholars a German and English speaking Forum that

- develops inter- and trans-disciplinary bodies of knowledge in the areas of medicine and the life sciences and makes these nationally and internationally available;
- supports young scientists through opening up a new field of work which runs across existing disciplinary structures;
- encourages the formation of *tandems* through co-authorship. In particular, it supports, evaluates and comments on collaborative projects with colleagues from the natural and engineering sciences.

The series is directed towards scholars and students from both the empirical science/social studies and the natural sciences and medicine.

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Rethinking Biomedicine and Governance in Africa

Contributions from Anthropology

Sleeping Sickness and the Limits of 'Biological Citizenship'

PETER REDFIELD

"Best Science for the Most Neglected"

DRUGS FOR NEGLECTED DISEASES INITIATIVE BROCHURE, 2004

Can one be a "citizen" of a neglected disease? For anyone positioned outside a particular strand of academic discussion relating health and politics, the question might appear counterintuitive, if not oddly contradictory. Nonetheless, at a historical moment when appeals to "global health" resonate powerfully through state and private philanthropy, when pharmaceutical products constitute a normal (and at times vital) component of daily routine, and when rhetorics of victimization and trauma underscore claims to compensation, political status appears increasingly attached to bodily condition. Indeed, recent work focused on problems of governance, bodies and transnational forms has proposed a clutch of variations on the theme of citizenship to identify medical politics of the present. Thus we might consider an individual to be—in acutely pragmatic terms—a "biological" citizen in the aftermath of the Chernobyl disaster in Ukraine, or a "therapeutic" one when surviving on imported anti-retroviral medications in West Africa (see Petryna 2002; Nguyen 2004 and 2010; Biehl 2007; Ecks 2008). What, however, about a less publicized threat, positioned at the edge of both biomedical and political concern?

In the essay that follows I will situate this question by examining a particular condition, human African trypanosomiasis (HAT) or sleeping sickness.¹ Once a classic colonial anxiety, sleeping sickness now finds representation in global health circles as a "neglected" disease, meaning that it primarily afflicts poor, marginal populations and consequently receives little attention or research investment. By comparing recent NGO efforts to combat the disease with

¹ | Sleeping sickness appears in several forms, affecting both humans and nonhumans in different ways as outlined below. For most of this essay I will refer to the condition by its more evocative colloquial name rather than HAT.

earlier responses to it under British administration in Uganda, I seek to highlight the manner in which contemporary health initiatives may reflect an altered configuration of governance. I make two general claims: first that global health engenders, at best, a "distant" form of citizenship, constructed out of humanitarian concern rather than territorial projects of nation state or empire. Consequently it lies closer to the figure of the human than to that of a rights bearing subject. Second, I wish to suggest, and illustrate, how disease particularities matter when seeking to investigate and generalize about contemporary intersections between life and politics. Now positioned at one end of a spectrum of attention and neglect, sleeping sickness embodies the essence of a global humanitarianism practiced at a molecular level.

By pursuing sleeping sickness through the question of citizenship I thus seek to trace a limit to an otherwise productive trope, one that might in turn reveal another topography of emergent forms. In *The Politics of Life Itself*, perhaps the most general statement of the significance of life to contemporary political forms, Nikolas Rose devotes a chapter to the theme of biological citizenship. There he concludes that "new kinds of biological citizens—with new subjectivities, new politics and new ethics—are forming around contemporary developments in biomedicine," identifying this development with "a new space of hope and fear [...] around genetic and somatic individuality" (Rose 2007: 154). Rose is careful to specify that his analysis applies to what he terms "advanced liberal democracies"—settings like Britain, Germany or the United States where individuals lead lives suffused with biomedical care, legal regulation and market exchange. He further notes that in "residual social states" demand might focus on government support rather than entrepreneurial self-fashioning. Yet amid the epochal language inspired by epic new technologies, it is easy to forget other emerging futures, such as new scenarios surrounding even an old disease. Precisely because the term citizen is seductive and fertile, it merits not only extension, but also recognition of the limits of its translation.

Keeping with a theoretical lineage that I share, I follow Rose in referencing Michel Foucault's classic concept of "biopower" and examining an assemblage of actors concerned with fostering the life of a given population (see e.g. Foucault 2003; Rabinow/Rose 2006). The perspective of a particular, marginal condition like sleeping sickness, however, suggests a rather different biopolitical vision—or set of visions—than either Foucault's account of early modern Europe or Rose's depiction of its genealogical descendants. As a vector driven disease confined to Africa, sleeping sickness inhabits a different historical sequence, one of colonial rule followed by postcolonial states and an aid regime. Citizenship here, then, bears a different relationship to other elements of

associative vocabulary, including "subject" and "human."² As I shall suggest, the latter is of particular consequence with regard to sleeping sickness. Notably, the contemporary humanitarian form of global health, constructed around a secular value of human life and typified by such entities as the Gates Foundation and the transnational NGO Médecins Sans Frontières, suggests a politics driven by moral claims. Thus political standing relative to global health—its "citizenship project" as it were—involves reference not only states and sovereigns, but also the longer arc of humanitarian concern for "suffering at a distance."³ The boundary lines of such a project do not conform to those of nation states, and involve a lineage of pity as much as rights.

My argument in brief is that international efforts to combat sleeping sickness increasingly claim the intrinsic value of human life. The human subject they imply is thus less the citizen of a nation state or the object of imperial rule, than the constituent of humanitarian concern. Since the sovereign responsible for the care of this subject's health appears incapable of protecting it, that health becomes the affair of other entities, including international and non-profit organizations, research scientists and pharmaceutical suppliers. In contrast to earlier biopolitical formations, life here stands at a remove from milieu. Citizenship in this context, I will suggest, may likewise stand at a remove from the liberal subject it implies, a distance measured in the space and time of "neglect." For advocates of global health, then, those suffering from sleeping sickness are emblematically human and yet only distantly and secondarily citizens. Their political weight appears at a remove, glimpsed through moral discourse asserting a right to receive the benefits of biomedicine (as practiced at the level of protocol standards and drug research), and through the abstracted, collective interest of the afflicted as a "stakeholder group." My goal in deploying the citizenship metaphor in this context is not to denounce humanitarian efforts to combat neglected diseases (a categorically noble effort from any perspective valuing human health) but rather to examine their political effects and parameters. Biomedical responses to sleeping sickness suggest a spiralling history, first from a hierarchical focus on biological pathogens to a more comprehensive ecological effort to cleanse territory, the breakdown of that control and a subsequent humanitarian focus on pharmaceutical agents. In the last case the biopolitical formation only constitutes a polity in a minimal and dispersed sense—citizenship "at a distance."

Over the following pages I offer three sketches of sleeping sickness. Two describe the disease from the contemporary perspective of a key medical

2 | See, e.g. debates surrounding Mahmood Mamdani's *Citizen and Subject: Contemporary Africa and the Legacy of Later Colonialism*.

3 | Phrasings borrowed from Rose 2007 and Boltanski 1999 [1993]. For more on the history of humanitarianism see e.g. Calhoun 2009; Redfield/Bornstein forthcoming.

humanitarian NGO, both at the level of a local project and the larger, global pharmaceutical effort to which it contributed. The other outlines the historical discovery and response to the disease under colonial rule. All three involve biomedical sensibilities and are set in the region now known as Uganda. By positioning each within a biopolitical frame, I suggest differences within their commonalities, ones that both distinguish the projects involved and reflect back on the concepts used to analyse them. In a fourth section I return to the conceit of citizenship to consider the problem of neglect in global health, along with the form of humanitarian science it inspires. While this approach emphasizes distinctions for analytical clarity, I do not intend to imply complete epochal shifts; a more complete accounting would recognize overlaps, inconsistencies and continuing negotiations.⁴ The goal here is simply to recognize political forms beyond nation state, and thus productively complicate the figure of citizenship.

SKETCH 1: A SITUATED CHALLENGE

First, a cursory ethnographic account. In the summer of 2003 I visited a sleeping sickness project in north-western Uganda.⁵ Founded over a decade and a half earlier by the humanitarian group Médecins Sans Frontières (Doctors Without Borders or, in native acronym, MSF), the project had shifted and altered course several times. By the point of my arrival MSF had officially handed clinical operations over to the Ugandan Ministry of Health, and only supported the last phase of a research study run by its epidemiological subsidiary, Epicentre. Although my visit was brief, as my first foray to an MSF field site it left a lasting impression and coloured subsequent encounters elsewhere. A pathos of loss associated with closure hung in the air; people pointed out where MSF previously had rented a house, staffed a clinic, adopted a dog. The sleeping sickness team went about its work with stoic determination, tinged with foreboding. Those now on the government's rolls complained about not being paid, while the rump Epicentre team repeatedly explained to health workers and patients alike why they were still screening but not directly enrolling or treating new subjects.

4 | For an example of historical complexity at the local level see Lwoba/Ombongi/Geissler/Malowany 2011.

5 | The material I draw on here stems from a larger ethnographic and historical study of MSF, with the bulk of research conducted between 2002-2006 in a number of sites in Europe and Uganda. Although actually a federation of 19 semi-autonomous national sections, for the purposes of this essay I will refer to the organization in the singular (this particular project in Uganda belonged to MSF-France, which also played a lead role promoting DNDi within the organization). See e.g. Redfield 2005 and 2006.

As the only non-Ugandan in the vehicle, I attracted shouts of children when we drove through remote hamlets, while the gaze of curiosity of their elders mingled with expectation: surely the white man in the white car would be in charge. The team's actual leader, an energetic Ugandan nurse I'll call Grace, stoically negotiated the tensions of being a younger woman instructing older men. Originally from the area herself she was intimately familiar with local languages and regional culture, a fact that she found a mixed blessing. She was glad at least to be working one district over from where most of her kin and classmates resided. Indeed, she eventually confided that her goal was one day to work for an NGO elsewhere—ideally far from a rural hospital in north-western Uganda—since she found there were problems with operating locally:

"I know the people here and they know me. They expect me to be just like them and to listen to their problems. At the same time the NGO wants you to perform a certain way. In town there would be nurses who were ahead of me; if I were in charge of them they wouldn't like it. It's much easier if you're from somewhere else and they don't know you."

Due to this background it had been difficult at first for her to take control of the remaining program. The staff, used to international leadership and doubting the ability of a young Ugandan woman, failed to show up on time and ignored direction, to the extent that one driver had to be fired. By now Grace had garnered sufficient respect to exert authority, but still found it a constant effort. Following this explanation I better understood her manner in wards and public settings like screenings, which I—used to a consumer oriented model of health care, alternately obsequious or indifferent—found startlingly authoritarian. She spoke in commanding tones and frequently in English, the national language of education. Her dress was inevitably "smart" in the British idiom. Like many Ugandans employed by MSF and other NGOs in positions of professional responsibility, she looked the part, in marked contrast to the casual, camping aesthetic favoured by international volunteers.

One morning we visited the stockroom of the local hospital to which Epicentre directed most sleeping sickness cases. Supply was clearly a problem: many shelves were bare and dusty, or had only one or two boxes or bottles on them, reminding me of stores I had seen in remote parts of Eastern Europe prior to 1989. Much of the visible supply sat in boxes marked MSF from their last delivery, which Grace anticipated would run out by the end of the year. A woman who worked there told us about their continuing problems with the authorized distributor, exemplified by a crisis over surgical gloves that the hospital's director resolved by buying a supply privately. Leaving the stockroom we ran into him, and he elaborated on the problem of sustainability as it pertained to the sleeping sickness program:

"At the moment we don't have special funding for this, but rely on what the ministry sends. Active screening and transport are expensive, so now we're just encouraging people to come in like with other diseases. We're trying to make sure we don't stop where MSF stopped, but try to continue where we can. But our limitations are national limitations."

While pleased to have trained personnel available, the director remained doubtful about the continued availability of drugs for treatment of the condition. At this regional level the question of drug access translated into basic problems of expense and unreliable transport. For him, sleeping sickness was simply another iteration of a general theme of inadequate supply.

Grace spent a good part of her day exhorting others to fulfil their duties. "With MSF it was like the police working," she told me, with a hint of wistfulness. "Almost all were treated; there was no reason not to. MSF would go and pick them [up]...with MSF there were no excuses not to get treated." The network of Sleeping Sickness Assistants had clear areas and well-defined responsibilities, and consequently followed up each case. In addition to free transport, those admitted received a food supplement courtesy of the World Food Program: beans, cooking oil, maize flour and sugar. The NGO also sponsored community education programs, not only about the disease but also about the need to support prevention efforts such as tsetse fly traps issued by the government.⁶ Since poor people remained likely to encounter flies in the course of daily subsistence activities—digging, fishing, herding cattle—they needed to leave traps in place, and not use their materials for other purposes. Moreover, if infected they should report promptly for treatment; although familiar with sleeping sickness in its debilitating later form, people remained reluctant to submit themselves to painful and expensive care until it proved unavoidable. Such a pattern was typical for all local health care, Grace noted, but with sleeping sickness such delay could prove fatal.

Now, however, everything was in decline. Individual actors might make efforts, such as one clinic struggling to maintain food supplements for example, if only flour and beans. The sleeping sickness staff continued to run screenings, check on cases and educate hospital staff and patients alike. ("Antibodies are the soldiers of the body!" Grace barked at a line of school children at one stop, "Ask your teacher.") However, even maintaining proper statistics remained an uphill struggle. Grace's team had a continuing disagreement with the district health administration over whose responsibility it was to calculate the local prevalence rate. After speaking at length with an official on the phone, Grace fumed that

6 | As the presence of these traps indicate, MSF's program did not run in strict isolation, but rather comprised a new, lively element amid layers of semi-active and historical programs.

no one read the reports she sent. Someone in the district office needed to go through the register book and district population records and calculate, not just call her at the last minute wanting a number for lobbying purposes. That was their job. The current information was hardly representative, she explained, showing me a paper that listed the hospital we had visited as having no cases, even though we had just seen some. If she gave officials a number they would quote it immediately, and should it prove wrong her credibility would be shot. A neighbouring district listed a prevalence rate of 12-15%, but no one believed that—it would be an epidemic!

My brief encounter with Grace's sleeping sickness team partly resonated with Foucault's classic formulation of biopower in dawn of liberal Europe. The disease clearly mobilized strategies related to the governance of life, generating a community of expertise, which in turn fostered strategies for a population to work on its own health. And yet in this context it would be a stretch to define such governance in terms of state action. Under NGO management and financing the experience of care resembled something like that of a liberal welfare state, minimalist, perhaps, but nonetheless comprehensive. Absent such subvention, however, the regular government apparatus offered few services, and even these functioned only intermittently. Uganda, even in its north-western reaches, hardly represented a "failed state"—indeed, by MSF's standards it was a relatively present and active one, requiring significant negotiation in such areas as customs controls and medical protocols. But likewise it was far less "biopolitical" than any contemporary European polity, in the sense of actively fostering life. Without intervention by other entities, some populations would likely be allowed to die. This prospect stemmed less from any exceptional action on the part of the state, than from quite ordinary facts of limited resources and logistical obstacles in a relatively poor, relatively populous country with eroded infrastructure. As a sleeping sickness patient one's national claims to benefits of citizenship remained distinctly limited. At the same time Ugandan professionals faced significant challenges in performing expertise appropriate to the work of governance. Grace experienced her local ties through the burden of received racial and gender norms, alongside the weight of expectations born of kin and tribal affiliation. For her (like many other Ugandans associated with the project), the state was an undependable figure at both national and regional levels, its agents alternately suspected of inattention, incompetence or corruption.⁷ NGO administration represented the prospect of effective procedures as well as reliable payment, a norm that clearly depended on ties to elsewhere. True biopolitics lay over the horizon.

7 | For discussion of tensions surrounding the contemporary African state see e.g. Ferguson 2006.

SKETCH 2: A COLONIAL MIRROR?

Given that sleeping sickness carries the colonial resonance of a pith helmet, the condition begs comparative examination through time. Here I will briefly review some of the history of biomedical efforts to respond to the disease and their relation to governance of life.⁸ In its concern and techniques MSF's medical project might mirror earlier interventions, but it suggests a different political geography than the configuration of high imperial rule, where concerns over security and labour dictated attention to milieu and population movements.

Between 1900 and 1905 an epidemic of sleeping sickness swept through Uganda, then a British protectorate. Perhaps a quarter of a million people died, arousing concern among colonial authorities. The Royal Society dispatched a research team to investigate, and in October of 1902 they identified a "fish-like parasite" in a blood sample, matching the trypanosome discovery made in Ghana less than a year before (Lyons 1992). Although accounts of a distinctive "African lethargy" had appeared centuries earlier, sometimes credited with emptying whole villages, this was the critical moment in the biomedical definition of the disease. Having linked the pathology with a parasitic infection, researchers subsequently identified the tsetse fly as the insect vector of transmission.

Initially unsure of the disease's potential to spread, the British government feared infection flowing up the Nile to India and struggled to come up with appropriate administrative measures in response. Other European powers watched warily and followed suit, partly for propagandistic reasons. To Uganda's west in the Belgian Congo, King Leopold saw the benefits of improving the image of his ruthless colonial venture with a public health service and invited the Liverpool School to send an expedition. At the same time some early researchers recognized that that sleeping sickness had achieved epidemic form precisely because of imperial expansion, and the disruptive effects of population migrations and invasive expeditions (ibid.: 72-75).

Over the ensuing years further scientific research revealed an increasingly complex picture of sleeping sickness. The form initially identified in the Ugandan epidemic, *Trypanosoma brucei gambiense*, acquired a sibling in 1910 with the identification of *Trypanosoma brucei rhodesiense* in Northern Rhodesia.⁹ Although similar in their ultimate effects on human health, the two differed in the precise nature of their vectors (different species of tsetse flies), their favoured climatic conditions (moist riverbanks vs. arid savannahs), their primary reservoir

8 | A more comprehensive historical presentation would incorporate additional threads, such as sleeping sickness control by the later colonial and postcolonial state, and the MSF's ties to French colonial medicine. See Lachenal/Taithe 2009.

9 | Precisely which form produced the Ugandan epidemic is now less clear (see Fèvre et al. 2004).

hosts (human vs. animal) and the speed of their onslaught (a matter of months or years vs. weeks). The human form of this disease divided Africa rather neatly west to east, with Uganda on the fault line between "chronic" Gambian and "acute" Rhodesian varieties. In addition, other trypanosomes infected livestock, also to devastating effect. From the perspective of colonial administrators all forms constituted a threat to their project of rule. In medical terms the human varieties were hard to detect without screening, particularly the slower acting *gambiense* strain. If left untreated, however, in both varieties the infection would ultimately move beyond the lymph nodes and cross the blood-brain barrier. Sleeping sickness thus proved a fearsomely fatal disease. Researchers gradually came to realize that its prevalence, however, depended on a relatively delicate balance between parasite, fly vector, environment and human host. Only under certain conditions—e.g. temperature range, intervals of feeding—could the parasite properly develop in the fly's gut and subsequently infect its human host. By and large, the collapse of stable settlement offered ideal opportunities for the spread of the pathogen. At the same time it could not spread indefinitely, or range far from its regional habitat (Hoppe 2003; see also Lyons 1992; Ford 1971). Both Europe and India, it turned out, were safe from this African scourge. Most Africans were safe as well, so long as they inhabited stably settled and well-cleared land. Ecologically constricted and yet potentially mortal, sleeping sickness proved a quintessentially colonial condition.

Along with the British, Belgian, French, Portuguese and German colonial administrations all developed and maintained efforts to control and combat the disease, sharing information and techniques. These approaches took two forms, one "medical" and the other "biological"—what would now be termed ecological (Hoppe 2003). In addition to research the first involved screening examinations to identify infected patients and the administration of drugs to treat them. By contrast the second sought to destroy the fly vector, eliminating its habitat and removing people from its vicinity. Generally speaking, the British emphasized ecological measures more than other colonial powers, seeking to restrict the movements of both human and fly populations. While the British might focus on limiting trypanosome carrying tsetse flies and the Germans and French on developing medicines, at moments of outbreak all sought quarantine and social control, embarking on sanitation campaigns to protect public health (ibid).¹⁰

10 | In a review of Hoppe's book, Imperato suggests the difference stems in part from the fact that the British in East Africa dealt with the *rhodesiense* form. While simplified, the point merits further investigation, as a suggestion by both author and reviewer that the temporary disappearance of sleeping sickness in the 1960s and 70s might stem from a decline of surveillance by newly independent African states (Imperato 2005; see also Hoppe 2003; Tilley 2004).

The motivation of these colonial interventions, however, was not simply humanitarian, or primarily concerned with human suffering. Rather, these actions retained a resolutely economic and social perspective, focusing on disease outbreaks as a structural threat. To quote Megan Vaughn:

"In the first half of the twentieth century any contact which the majority of Africans had with colonial medicine was likely to have been in the form of a 'great campaign'. Epidemics of smallpox, of meningitis, of plague, and of sleeping sickness posed a constant threat to the economic (and political) viability of the early colonial state. The rise of tropical medical research was an outcome not merely of the elevation of germ theory, but of the continuing threat posed by epidemic disease to the entire colonial enterprise." (Vaughn 1991: 37)

By definition, the political economy of empire concerned itself with place, investing expectations in defined territories. The results were indeed productive, if not always in the economic sense. Research associated with these colonial health interventions contributed to early understandings of disease ecology (Tilley 2004; see also Anderson 2004). Thus while key compounds to combat sleeping sickness emerged during the era of colonial governance (e.g. the venerable drug melarsoprol), they did so amid a broader effort to remake humans and their landscape. The project of saving lives blurred with that of transforming them, to the calculable benefit of a larger enterprise. As a talk for the United Fruit Company once baldly put it: "the future of imperialism lay with the microscope" (cited in Lyons 1992: 69, 267).

The colonial experience of sleeping sickness, then, suggests something of a biopolitical regime—however fragmentary and incomplete—but one that remained inseparable from the work of ordering territory. Combating a problem likely exacerbated by the very disruptions they fostered, European administrators encouraged the development of expertise related to this condition under the name of "tropical" medicine.¹¹ This expertise subsequently generated truth about human life and health and directed interventions in their name. The subjects produced may have been colonial rather than liberal, i.e. potential rather than actual citizens, possessing few if any rights and requiring paternalistic oversight. The objects of concern may have remained the crude disruptions of epidemic disease, rather than finer grained measures of a population's health. Nonetheless, sleeping sickness inspired strategies to govern life on the part of colonial authorities, ones moreover that would prove remarkably durable. In this sense colonial efforts to combat the disease recall something of Foucault's

11 | For once not a misnomer, given the regional restriction of sleeping sickness, unlike other "tropical" conditions with broader geographic range and frequently associated with poverty, e.g. cholera, malaria etc. (Lyons 1992: 68; see also Worboys 1994).

classic sketch of biopower. In contrast to the European case, however, here strategies of governance continued to prioritize epidemics, and focused on colonial rather than national populations.¹² These were hardly the emerging states of Rose's "advanced liberal democracies," however much they remained linked through colonial rule.

SKETCH 3: A GLOBAL CONCERN

Returning to the ethnographic present, I will now widen the focus and lengthen the timeline for my particular case. Despite Grace's reluctance to produce numbers on demand, the shepherding of statistics was her primary role at the time of my visit. Epicentre's studies sought to analyse the effectiveness of different protocols used by MSF's project in the treatment of sleeping sickness. The efforts of the remaining team ensured that two decades of clinical work would translate into scientific medicine, not only enhancing MSF's expertise with the condition but also encouraging a renewed commitment to pharmaceutical development related to it. Analysed and eventually published, some of the data would make a strong case for alternative therapies to melarsoprol, the highly unpleasant and hazardous compound derived from arsenic used to treat the deadly second stage of the disease (MSF 2006; Checchi et al. 2007). More generally, it would also contribute to MSF's worldwide endeavour to improve access to essential medicines and foster research on "neglected" diseases. To explain this latter significance, I need to backtrack and pursue the larger story of this emerging humanitarian concern.

In 1986-7, when MSF first began its sleeping sickness project in Uganda, the organization was still relatively small and almost entirely focused on projects providing basic health care in crisis settings, usually to refugee populations. The group had already experienced a series of acrimonious splits since its founding in 1971, and recent controversy in the form of the very public eviction of the original French branch from Ethiopia. In response MSF initiated an array of initiatives during the late 1980s to enhance its professionalism, developing a standardized logistical system and incorporating public health and epidemiological knowledge. To that end a member who had studied at Johns Hopkins University (and worked at the Centres for Disease Control in the United States) helped set up Epicentre. Although nominally independent, it would primarily serve MSF's interests by producing rapid, targeted studies on demand.

In Uganda, where the French section had been running refugee projects in the northwest of the country, the political situation slowly stabilized after a

12 | Foucault describes the shift in Europe between a concern for epidemics to "endemics" (Foucault 2003: 199; see also Rabinow/Rose 2006: 199).

period of turmoil following the fall of Idi Amin. As the refugee project wound down, the group decided to launch the sleeping sickness venture, due both to a noticeable rise in prevalence, and to the contingent fact that a key doctor involved had written his medical thesis on the disease. Long considered endemic to the area, sleeping sickness re-emerged as a problem during the period of upheaval in the early 1980s, due to the movement of refugees in both directions across the Uganda and Sudan border, the collapse of control programs and health infrastructure and the decline in land cultivation. Tsetse flies, it turned out, thrived on civil war (Priotto/Kaboyo 2002).

The resulting project would evolve in a series of different sites in the same general region, and incorporate a research element alongside its clinical practice. In this regard it contrasted with MSF's "classic" emergency missions, and at times resembled efforts at community health development, a form of engagement from which the organization (and especially the French section in question) generally distanced itself. For this particular project the NGO saw itself working in partnership with the Ugandan Ministry of Health, providing one part of a more comprehensive effort to combat the disease. By training a network of personnel it would also aid the larger cause of rebuilding the country's health infrastructure. The project ended up lasting a remarkably long time, shifting locations in response to its own success in lowering local prevalence rates. It also evolved to gradually emphasize research. By focusing on this specific disease, MSF became increasingly aware that the prevailing medical protocol was a problem. Not only did melarsoprol fail to work in over a quarter of the cases, it also ended up killing some 5% or more of those treated (Priotto/Kaboyo 2002). In addition, few alternatives had appeared in the pharmaceutical pipeline. As a vector driven disease confined to marginal habitats, sleeping sickness almost exclusively afflicted poor populations; consequently it offered little prospect for profit and was of little interest to commercial drug companies. Labouring in the fields of frontline medicine, MSF thus discovered a fundamental weakness in the infrastructure of international health.

The sleeping sickness program proved emblematic. By approaching its work more epidemiologically and treating key diseases over time, MSF began to recognize recurring patterns of failure associated with drug resistance in its mission sites, and the importance of affecting official protocols. At the same time its essential drug supply proved increasingly uncertain. Within some quarters of the organization (particularly the ancestral French section), concern was rising over the perennial problem of unequal access to medicines, as well as a general lack of drugs to combat unprofitable conditions. Another pivotal step towards MSF's pharmaceutical epiphany had occurred in the early 1990s. Combating meningitis in Sudan MSF found that its usual treatment, oily chloramphenicol, did not translate into the former British Empire, where protocols inherited from the colonial era favoured ampicillin instead. To justify

the French preference Epicentre conducted a study demonstrating the French treatment's effectiveness, while NGOs lobbied the World Health Organization to include oily chloramphenicol on its list of essential medicines. At the very moment of triumph in 1995, however, the manufacturer of the drug abruptly decided to cease production after finding its profit margin too minimal. The scramble to find an alternative supply confirmed the significance of drug issues, while bringing the group in closer contact with generic manufacturers and the assistance of the International Dispensary Association.¹³ Over the ensuing years MSF sponsored a conference and subsequently formed a working group to address the issue. By the late 1990s MSF had dropped its earlier resistance to HIV/AIDS work and increasingly involved itself in campaigns to combat that spreading pandemic. In 1999—on the eve of receiving the Nobel Peace Prize—MSF launched a "Campaign for Access to Essential Medicines," denouncing global inequities in biomedical supplies, and demanding new measures to address the problem. The subsequent award of the prize, together with the publicity and funds it generated, helped fuel the rapid growth of MSF's advocacy work over the ensuing years.

From its inception the Access Campaign included an even more significant departure for the MSF movement: a collaborative effort to directly fund and coordinate the research and development of drugs for "neglected" diseases. Surveying the greater terrain of human afflictions from a global perspective, MSF distinguished four categories of conditions relative to the pharmaceutical market (MSF 2001). The first was that of "global diseases," maladies such as cancer or cardiovascular disorders that affect all populations, including wealthy ones where profits could be made. Unsurprisingly, the focus of pharmaceutical corporations rested here. MSF's second category was that of "neglected diseases," maladies such as malaria and tuberculosis that might occasionally strike people who live in wealthy countries, but largely affect poorer ones. Such conditions remained generally marginal to pharmaceutical profits and hence research. The third category was that of "most neglected diseases," vector driven maladies such as sleeping sickness and leishmaniasis that exclusively afflict the marginal poor. Offering little opportunity for profit, these conditions received almost no corporate attention. The fourth and final category was that of conditions "other than purely medical," defects such as wrinkles, cellulite or baldness that obsess wealthy populations and thus have constituted a growing area of commercial drug research (*ibid*).

Facing this constellation of diseases only partially addressed by commercial drug development, MSF eventually decided to join with several partner organizations and launch an effort known as the Drugs for Neglected Diseases

13 | I owe this account to the excellent interview conducted by Johanna Rankin in her unpublished honours thesis (Rankin 2005 esp.: 93-96 and interview in Appendix A).

Initiative (DNDi).¹⁴ Incorporated as legal entity in Geneva in July of 2003, DNDi began the task of identifying both shorter and longer-term projects that would modify or enlarge the arsenal of medications available to combat neglected diseases, especially the most neglected. Rather than plunging directly into comprehensive research and development itself, the initiative sought to operate as a virtual drug development organization, eliciting, supporting and coordinating a portfolio of projects within existing infrastructures. The goal was to circumvent the marketplace by focusing on medical need and treating drugs as "public goods."

Throughout the development of MSF's Access Campaign and DNDi, the group's on-going project on sleeping sickness played a prototypical role. Indeed, as an MSF administrator told me in Paris in 2003, "sleeping sickness really was the Access Campaign before it existed." As it continued to expand its research portfolio to include other diseases like malaria, Epicentre established a field station in Uganda. Some key figures within MSF spent formative years in the country, becoming familiar with the mission. At the same time the drug eflornithine also became a topic of public controversy. Originally developed as a cancer treatment, eflornithine emerged as a key alternative to melarsoprol in treating the later stage of sleeping sickness. However, its manufacturer, Aventis, discontinued production in 1995 after finding the drug non-profitable. Following lobbying by MSF and WHO (as well as a famously fortuitous discovery that the compound could also treat unwanted facial hair in postmenopausal women) manufacture resumed in 2001. The terms of the agreement guaranteed availability of a supply designated for the treatment of sleeping sickness, at least for the short term.¹⁵ This minor victory—like the larger struggle over AIDS drugs around the same time—suggested the potential of a pharmaceutically focused humanitarianism. Beyond suffering individuals and endangered collectives, MSF could defend life in the form of "neglected diseases" and the resources needed to combat them.

Who, however, would speak for a dispersed, impoverished population of sleeping sickness patients at the level of pharmaceutical research? Unlike with AIDS, there was no ready group of vocal community advocates, demanding to be heard. While in Geneva in the fall of 2004, I paid a visit to the offices of DNDi. Little more than a year old at that point, the organization still exhibited signs of

14 | In addition to MSF, founding partners in DNDi included the Oswaldo Cruz Foundation in Brazil, The Indian Council of Medical Research, the Institut Pasteur in France, the Malaysian Ministry of Health and the Kenyan Medical Research Institute. The new organization also worked in association with the UN-World Bank-WHO program known as TDR (Research and Training in Tropical Diseases). For further details see the DNDi website (www.dndi.org).

15 | MSF press release, May 3, 2001, "Supply of Sleeping Sickness Drugs Confirmed."

hurried growth, if far less frenzied than in most MSF settings. The atmosphere struck me as distinctly more sedate and corporate, befitting the pharmaceutical focus and institutional timeline. A cheerful young woman responsible for communications gave me a briefing, outlining their early prospects and future plans. One key question, she noted, was how to compose their advisory board. DNDi was keen to include a patient representative. Although the organization felt it had a pyramid of networks to draw upon, having one person to report to the board would be ideal for consultations in the context of meetings. Identifying an appropriate individual to play this role, however, was proving difficult:

"We're shooting for the moon, finding someone who can represent three diseases and three continents. The patient's voice needs to be heard. For example one leishmaniasis drug is available but prohibitively expensive. Also hospitalization is expensive. People don't think of these things when developing drugs. We need to identify one person on each continent to discuss such issues. We obviously want Nelson Mandela, Kofi Anan and Jesus Christ rolled into one. We need a Superman or Superwoman [...] someone who can speak a world language, but also comes from a local one. It's a challenge to find such a person, to put it politely."

At the same time, the organization did not have an industry representative on its board. "It's the shadow of MSF," she explained, "it's given us enormous credibility, but also flak we have to endure." Recognizing the deep-seated mistrust between their parent NGO and the entity it conceived of as "Big Pharma," she felt tension would die down in the context of DNDi discussions, where the goal of nonprofit drug development could dovetail with industrial desires to exhibit corporate citizenship. Still, she noted, there remained an essential difference between profit-making and what she termed "obscene profits." For MSF "how much is enough" was not rhetorical question but a moral boundary.

DNDi (along with similar recent efforts to foster nonprofit drug development for unprofitable diseases) suggests still another, narrowed and distanced variation on the larger theme of biopolitics.¹⁶ Here intergovernmental and

16 | A number of recent initiatives have focused philanthropic and humanitarian energy on providing the world's poor with greater access to pharmaceutical products. Joining older entities like the TDR (Special Programme for Research and Training in Tropical Disease, established by the WHO and other international entities in Geneva in 1975), and the IDA (International Dispensary Association, begun by pharmacists in Amsterdam in 1972), this newer wave of acronyms focuses on developing treatments for specific diseases afflicting poor populations through mobilizing "public private partnerships." The Bill and Melinda Gates Foundation has played a central funding role, providing substantial support to the MMV (Medicines for Malaria Venture, started in Geneva, 1999), OWH, (One World Health, San Francisco, 2000), the TB Alliance (Global Alliance

nongovernmental actors play a central role in fostering life for given populations, constituted through infection with a particular disease rather than by territory. The focus of these projects rests directly on ensuring access to effective remedies for this specific condition, not on a more comprehensive effort to improve general hygiene or alter community life around it. At the same time the overall vision connects life and politics as a matter of course. If a state or interstate agency fails to fulfil biopolitical expectations, that failure is now understood in relation to the particular form of the state more than to the normative project of health governance. Thus a disease that does not enjoy attention by state and interstate entities acquires the revealing designation of being "neglected." By further addressing market failures that produce medical neglect, non-profit drug initiatives acquire a moral tone, seeking—as of DNDi's slogans has it—to produce the "best science for the most neglected." This secular echo of Christian reprioritization inspires a highly specific and attenuated array of interventions. It involves states as secondary partners rather than targets, enrolls corporations as well as chiding them, and defines populations in medically differentiated terms. As a biopolitical project, then, it remains a restricted endeavour, a meeting ground for diffused experts and good will, not the engine of an expanding, bounded state.

The work of non-profit pharmaceutical development does suggest an identity project of sorts, but one detached from any particular national context and restricted to a population constituted by a disease. Moreover, this project derives neither from popular pressure, nor from state imposition. Instead it takes shape amid an assemblage of international actors and moral sentiment—sideways and at a distance, as it were, rather than bottom up or top down. The desire to enrol representative subjects remains a part of the endeavour, if somewhat as an afterthought. Even when framing survival as a molecular issue, DNDi still seeks to assure some measure of self-representation of patient interests. The degree to which this proved challenging in practice, however, only underscores the displacement involved. Only a "Superman or Superwoman" could properly articulate "the patient's voice" for a neglected disease.¹⁷

for TB Drug Development, run between New York, Brussels and Cape Town, 2000), the DNDi (Drugs for Neglected Diseases Initiative, established in Geneva 2003), and a looser consortium of researchers led by UNC-Chapel Hill (2000).

17 | In 2005 DNDi announced that a woman from Ghana had joined their board as a patient representative. See DNDi Newsletter Number 12, November 2005. <http://www.dndi.org/newsletters/12/news.htm>

GLOBAL HEALTH, DISTANCE AND THE LIMITS OF CITIZENSHIP

Thus far I have suggested variations on the theme of biopolitics as they appear relative to different projects responding to sleeping sickness. I now wish to examine the contemporary topic of neglect more closely, by elaborating on "distance" relative to citizenship and the moral politics of global health.¹⁸ In his book *Distant Suffering*, Luc Boltanski takes up and extends Hannah Arendt's observations about the "politics of pity." Pity, for Arendt, ignores questions of justice, concentrating instead on the fact of suffering. It does so, however, at a remove and en masse, unlike say, the grief of a parent for a child or the compassion displayed between particular, situated individuals. By generalizing suffering in this way, pity opens a problem of distance for the public it constitutes, one it seeks to resolve through eloquence and sentiment (Boltanski 1990 [1961]; see also Arendt 1990 [1961]). Boltanski is particularly concerned with this "dimension" of distance and its effects on the capacity of a moral spectator for action. He frames his meditation on media and political theory through reference to a classic scenario of contemporary suffering: the drama of "humanitarian emergency" as scripted by international broadcast over the last decades of the 20th century. This is precisely the terrain upon which MSF emerged following spectacles of suffering in Biafra and Bangladesh, and to which it has represented a continuing form of medical response.

In its emergency mode, MSF has certainly embodied something like a politics of pity (albeit stripped of the ruthlessness of Robespierre), being intimately aligned with media spectacle and tightly focused on the present. Like all humanitarian organizations it defines its engagement in ethical terms, through a fundamental concern for human suffering and a refusal of justifications for it. Once properly channelled through a project, this moral logic goes, human feeling might bridge distance with action, allowing something like individuated compassion to emerge. Relative to other groups MSF is outspoken and relatively concerned with political effects. Nonetheless, it is important to note that MSF does not offer political remedies. The NGO may provide temporary, limited governance related to health, but from the organization's perspective political responsibility lies emphatically elsewhere, with nation states and intergovernmental organizations. MSF's volunteers and donors—even its national staff in their professional capacity—remain at a political distance from general problems of any given territory. With the end of an emergency the structures of their minimal governance of life evaporate, re-condensing in the next crisis.

18 | I have found essays by Jeremy Greene, Andrew Lakoff and Tobias Rees quite helpful thinking beyond about "global health" as a contemporary formation, and thank the authors for sharing them. See Lakoff 2010: 59-79.

MSF's move to advocate for pharmaceutical equity and sponsor DNDi, however, suggests a slightly altered configuration of humanitarianism, one attuned to market failure as well as political disruption and cast on a longer timeline. The primary referent is less that of visible disaster than of slower moving structural inequities, the stark inequities that belie humanitarian assertions about the value of life (see Fassin 2007). This configuration may still define suffering as an exceptional state, but not necessarily as an emergency in the medical sense, where procedures are standardized and every moment counts. Rather, it fits into a larger assemblage of global health, advocating policy initiatives and sponsoring laboratory research. Appropriately for an era of "biocapital" and "twenty-first century biomedicine" it also implies a measure of standing based on medical condition and research (Rajan 2006; Rose 2007). Mobilizing a global conception of humanity, this citizenship applies an international scale. Its political frame is not a nation state or empire, but something far more dispersed, appearing in far-flung meeting rooms and pharmaceutical compounds. The political weight of this humanitarian configuration and the degree of its local purchase vary, however, depending on the nature of the condition addressed.

Beneath its unified array of brochures asserting the human need for essential medicines, MSF's Access Campaign bridges a number of tensions between different diseases. These tensions emerged in debates within DNDi over what constituted a truly "neglected" disease. Would HIV-AIDS, or even malaria count, despite the considerable attention and media exposure each inspired? However coherent as a moral project—eloquently defined around the worth of human life—the humanitarian strain of global health is hardly a singular or unified enterprise in practice. Cholera, Ebola and HIV-AIDS, for example, inspire different responses at both technical and political levels, producing different constituencies and possibilities. Cholera, a classic health concern in refugee settings and relatively simple target for biomedical hygiene, helped prompt MSF to create a mobile kit system of emergency logistics (see Redfield 2008). Ebola, a comparatively new condition with uncertain risks, has commanded the attention of international media, security planners and the CDC as well as MSF. And HIV-AIDS, of course, has famously produced a vast array of social movements and organizations, fuelling the larger pharmaceutical out of which MSF's Access Campaign arose. The fact that all three conditions appear in Uganda, or within this particular NGO's portfolio, does little to erase significant distinctions between them.

To illustrate this last point I will expand slightly on the comparison between HIV-AIDS and sleeping sickness. Just down the road from its atrophied sleeping sickness project, MSF had opened an AIDS clinic to offer free anti-retroviral treatment to selected patients in the region. In contrast with the Epicentre study, this venture burgeoned with new patients and an expansive sense of the

future. Part of the organization's decision to roll out such programs worldwide beginning in 2000, the clinic also reflected a wider sea change related to ARV treatment at the time.¹⁹ Fuelled by the stark contrast between prospects for rich and poor patients with the same disease, a moral campaign by heterogeneous group of actors—including MSF—helped lower drug prices and suggested new norms, both of treatment and global health (See, e.g. Whyte/van der Geest/Hardon 2002; Petryna/Lakoff/Kleinman 2006). The moment marked a conversion for the organization as well. Although sponsoring a few projects earlier in the 1990s (including an local NGO involving traditional healers in Uganda), MSF had largely kept its distance from AIDS work prior to the advent of ARVs, feeling both that the disease received ample attention and fell outside their technical expertise. Once treatment became available, however, pressure mounted inside and outside the organization and a different logic took sway: surely the threat of pandemic disease merited equal attention to the threat of disaster.

Like sleeping sickness, AIDS was not an emergency in MSF's terms; to combat it the organization would need to develop new techniques, conduct research and alter its practice and timeline, accepting a far longer commitment than its classic norm. Both also led to a focus on pharmaceuticals, including the protocols governing their delivery and the infrastructure that permitted their availability. A crucial distinction, however, lay in the scope of transmission for the two diseases and the sense of vulnerability each might inspire. Although far from evenly distributed, the risk of HIV infection stretched worldwide, into rich as well as poor settings. Claims by or on behalf of AIDS patients mobilized a broad constituency; the condition was not distant from the experience of middle class spectators and many shared a potential need for the same medication. Thus any citizenship projects AIDS might inspire would include measures of shared risk and potential profit. Sleeping sickness, by contrast, constituted a regional problem from the perspective of global health, and even in Uganda primarily concerned a marginal population. Its constituency therefore has remained narrow, only exacerbated by the fact that in its later stages the disease's very symptoms impair the ability of patients to represent themselves. Thus any citizenship projects sleeping sickness might inspire depend more strictly on moral sentiment and claims made on behalf of others, in this instance via common humanity and the value of life.

For MSF the essential break between the AIDS and sleeping sickness surfaced when DNDi emerged as a distinct entity. As my contact at the organization helpfully pointed out, people might talk about AIDS, TB and malaria as underserved,

19 | The Arua clinic began offering ARVs in 2002, and in a recent count had well over 4000 under treatment, part of the 100,000 MSF supports worldwide in 2009. See (<http://doctorswithoutborders.org/news/issue.cfm?id=2392>)

neglected conditions. Nonetheless, degrees of "neglect" varied significantly, she noted: "The most neglected diseases, however, no one is interested in them at all. That's why there's no AIDS in [our] portfolio."²⁰ After all, by 2004 AIDS clearly aroused considerable interest. By contrast, a century after British colonial medicine feverishly deployed its microscopes "no one" cared about sleeping sickness. In launching a project to address this oversight, then, humanitarianism could rediscover the disease precisely in the distance of its neglect, and the moral claim of those afflicted to pharmaceutical production. The result might be biopolitical in a general sense and operate in the shadow of biocapital. But it would be unlikely to contribute much to the formation of a states or the dissolution of markets. Rather, it would remain a matter of more modest ethical claims.

CONCLUSION

To ask whether or not one can be a "citizen" of a neglected disease leads less to any definitive answer than to a reformulation of the question. Taken seriously, it recalls the work of translation involved in resituating theory, the extent to which displacement reorients terms by revealing their assumptions and limits. Citizenship implies a particular form of polity as well as standing within it. Neglect implies normative expectations of treatment as well as the failure to provide it. And the specificities of a condition like sleeping sickness suggest that with it biological citizenship reaches a limit, becoming a suggestive point on the horizon of possibility rather than a substantive condition. In an era oriented by the global pandemic of AIDS, it is particularly important to recall that some diseases present more opportunities for political recognition than others. When sleeping sickness threatened control over territory, it was a political problem of empire, one that subsequently framed the inheritance of postcolonial states. Now thought to endanger only marginal regions of poor countries, it has become an ethical problem of humanitarian action, the concern of NGOs as much as governments.

Alongside the citizen, then, we should place two other conceptual figures: the subject and the human. The former proves particularly relevant at the contemporary moment, when governance projects related to health have supplanted territorial projects of rule. The human, after all, is a figure of ethical as well as political claims. It lends itself to moral enterprise under secular worldviews. The form of "citizenship" it offers extends beyond a given milieu or particular nation state, being primarily an assertion of universal rights and

20 | DNDI's portfolio at the time concentrated on three parasitic conditions (sleeping sickness, kala azar and Chagas disease), as well as some work on malaria. For current projects see <http://www.dndi.org/>.

dignity. It is, in this fundamental sense, a distant condition. The cases sketched in this essay suggest shifting aspects of such distance: its value in performing expertise, its practical application in the practice of colonial rule, and its thinness with respect to political representation.

To conclude, then, I return to a classic appraisal of the fateful line between citizen and human. In the wake of the Second World War, Hannah Arendt famously compared the promised rights of man with actual rights of citizenship, and found the former sorely wanting. Real political status, she suggested, depended on membership in a polity; without it one was human only in abstract terms, and consequently lacking the essential capacity for public life. The dilemma of stateless people, Arendt trenchantly observed, derived less from the loss of particular rights than from the loss of a state. Only citizenship held out any hope of meaningful representation, and through it any claim for equality. Reprising Burke's scepticism about the abstract guarantees of the Rights of Man, she noted caustically that when put to the test "[t]he world found nothing sacred in the abstract nakedness of being human" (Arendt 1973: 299). Despite the general prescience of her observations regarding statelessness, we might amend her words for an era of humanitarian intervention and global health. Now the abstract nakedness of distant others suggests moral value in the form of a drug—providing, of course, they have a parasitic disease.