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Bodies of Rights and Therapeutic Markets

Justice does not exist! Human Rights do not exist. What matters is jurisprudence. This is the invention of Law. . . . The challenge is to create and not to make Human Rights applicable. It is a matter of inventing jurisprudences so that, for each case, such and such thing could not have been possible. . . . Many times, life can be seen case by case. . . . It is not a matter of right of this or of that, but of situations that evolve . . . to struggle for jurisprudence . . . to create the right.

—Gilles Deleuze¹

ENTERING JUSTICE, ONE BY ONE

SEVEN CHILDREN LAY IN A HOSPITAL ROOM HOOKED UP TO AN intravenous drip. Their parents stand near them, bantering with each other and with the doctors who circulate in and out. Every week these parents bring their young children, who suffer from a disorder called mucopolysaccharidosis (MPS), here to the Research Unit of Hospital Universitário, a public hospital in Porto Alegre, the capital of the southern state of Rio Grande do Sul, Brazil.² The children are receiv-

We are deeply grateful to Joseph J. Amon and Mariana Social for their insights and help. We also thank Roberta Grudzinski, Peter Locke, Alex Gertner, Raphael Frankfurter, Jeferson Barbosa, and Ramah McKay for their research and editorial assistance. The Ford Foundation, Woodrow Wilson School, and Health Grand Challenges Initiative of Princeton University have generously supported this work.

ing enzyme replacement therapy (ERT) which can cost up to \$200,000 dollars per year per patient.³

MPS encompasses a group of inherited metabolic disorders in which mucopolysaccharide, a complex carbohydrate, builds up in body tissues in a dangerously nonmetabolized form due to the lack of activity of a specific enzyme (Beck 2007). MPS disorders affect approximately 1 in 25,000 individuals (Clarke 2008) and usually manifest themselves in early childhood. They are characterized by skeletal and joint deformities, growth stunting, and facial changes caused by accumulation of mucopolysaccharide in the underlying facial bone. MPS leads to neurological, cardiovascular, and respiratory impairments as well as liver and spleen enlargement, and hearing loss. Severe cases are fatal in the first decade of life and milder cases may have a normal lifespan but have significant disease morbidity (Clarke 2007). MPS disorders are not curable, but ERTs have proved useful in reducing some of their symptoms, improving quality of life and, in certain cases, increasing lifespan.

All these MPS children are patient-litigants. Their parents are suing the government so that they can receive treatment for life. In summer 2008, we spoke to multiple actors involved in this new and increasingly ubiquitous practice of litigation against the state for treatment access, a phenomenon known as the judicialization of the right to health. Though patients are suing all levels of government for everything from baby formula to complex surgeries, a large portion of lawsuits are for medicines.

Brazil is among the approximately 100 countries that recognize a constitutional right to health (Gauri and Brinks 2008). An important part of this right is access to medicines. Although Brazil has one of the world's most advanced HIV/AIDS treatment program, many of its citizens still go to local pharmacies only to find that essential medicines are not available. With a population of about 190 million people and an economy on the rise, today Brazil is one of the fastest growing pharmaceutical markets in the world, and doctors increasingly prescribe and patients demand new medical technologies.

Some MPS treatments have been approved by the U.S. Food and Drug Administration (FDA) and the Brazilian National Health Surveillance Agency (ANVISA); others are still in clinical trials.⁴ Biotechnology companies are entering the field of orphan-disease treatments, breaking new ground beyond the blockbuster model of drug development (Petryna 2009).⁵

Doctors at the hospital were excited about the possibilities of finally offering patients something more than just an accurate diagnosis of their genetic ailments. But they were also cautious about hyped claims of efficacy. “It is a new world,” said Dr. Maria, who monitors these children. “I think we are bringing new things from genetics to SUS [Brazil’s universal health care system]. Some here were in clinical trials but all are SUS patients now. To guarantee treatment access and to follow up on the effectiveness is very problematic.” The interests of clinical research, public health, and biomedical markets fold into the injured bodies of these young patient-citizen-litigants.

The children here come from low- and middle-income families that would never have been able to afford these genetic therapies. They obtain them as a result of lawsuits their parents filed against the state of Rio Grande do Sul in the name of the right to health. Article 196 of the 1988 democratic constitution affirms health as a right of the people and a duty of the state, “guaranteed by social and economic policies that reduce the risk of disease and other adversities and by universal and equal access to actions and services” (Constitution of the Federative Republic of Brazil). The parents told us that, in order to make the claim, they must have a diagnosis and medical documents proving the benefits of the costly treatment. In most cases, district judges immediately issue injunctions that force the state to provide the treatment for a month or two. A final ruling by the higher court might take several years as state prosecutors file multiple appeals, expert committees review medical evidence, and the case might find its circuitous way to the country’s Supreme Court in Brasília, the federal capital.

Only one of the seven children there has some of her infusions paid for by the drug manufacturer. Rita, who is 12 years old and “in a

near-vegetative state” (according to her mother Ilse), took part in the first clinical trial that led to drug approval in Brazil. In 2004, after the trial ended and the trial sponsor stopped providing the enzyme on a compassionate use basis, Rita became the first MPS patient-litigant in the state. She won an initial court injunction that had to be periodically renewed, since state prosecutors were appealing the ruling and the higher court had not yet reached a final decision. A physician told us that, in the meantime, the manufacturer had agreed to share the cost of Rita’s treatment with the state, most likely to avoid becoming a defendant in the higher court. For all these children, the uncertain and potentially fatal natural history of the disease now meshes with hope-inspiring, cutting-edge genetic therapies and a time-consuming juridical quest. The critical question of who will pay for the therapeutic—the family, the government, or the manufacturer—is bound to the creation of jurisprudence over the right to treatment.

The three-hour infusion time was over. The children were awake, talking and playing—except Rita. Her mother, Ilse, was caressing her face. As all MPS children there, Rita’s stature was short and her head was enlarged. The facial features were coarse and her skeleton slightly deformed. Her mental development “was delayed,” Ilse stated. A red folder containing the latest medical records and court rulings lay at Rita’s feet. “After the study ended, we contacted a private lawyer, Mr. Moura, and we filed a lawsuit against the state to get the enzyme. Other parents followed suit,” she said. “Rita is a citizen. Here in Brazil, she has the right to health.” Ilse, like the other parents in the infusion room, used the expression *entrar na justiça* “to enter the judiciary” (or literally, “to enter justice”) to refer to their lawsuits.

All over Brazil, patients are turning to courts to access prescribed medicines (Azevedo 2007; Colluci 2009). Although lawsuits secure access for thousands of people, at least temporarily, this judicialization of the right to health generates intensely complex sociomedical realities (as embodied by the MPS families) and significant administrative and fiscal challenges that, officials argue, have the potential to widen inequalities in health-care delivery (Ferraz 2009). In this article,

we explore how right-to-health litigation became (in the wake of a successful universal AIDS treatment policy) an alternative pathway for Brazilians to access health care, now understood as access to medicines that are either on government lists for pharmaceutical distribution or are only available through the market. Is the judicial system an effective venue to implement socioeconomic rights? Which practices of citizenship and governance are crystallized in these struggles over drug access and administrative accountability?

Government-purchased medicines make up a formidable market in Brazil and, as we show, treatment litigation happens in a context of a dysfunctional and decentralized public health system. The role of market forces in judicialization—a mix of pharmaceutical marketing strategies targeting physicians' prescriptions and fueling patient demand as well as limited regulatory oversight—must not be overlooked. But a key point here is that low-income patients are not just waiting for new and high-cost medical technologies to “trickle down”: they are using public legal assistance and the levers of a responsive judiciary to gain full access *now*.

The twin phenomena of the pharmaceuticalization of health care and the judicialization of socioeconomic rights raise crucial issues that are at the heart of global health debates today: technology access and care delivery, the financing and sustainability of treatment programs, the strengthening of health systems, and improving outcomes. We need a deeper understanding of the political economy of pharmaceuticals that informs large-scale treatment initiatives and how information, science, and technology impact health systems and life projects on the ground.

PHARMACEUTICALIZATION AND JUDICIALIZATION

In Brazil, the 1988 constitutional right to health was accompanied by the creation of the *Sistema Único de Saúde* (SUS), extending health coverage to all citizens. To improve the management of the public health care system, the Ministry of Health divided responsibilities for pharmaceutical distribution between three levels of government as part of a broader

process of decentralization. While the federal government retained some of its central role in financing public health (administering some high-priority disease programs that required high-cost treatments), state and municipal health secretariats had to develop new structures to assess health needs and to administer federal and local funds for drug provision. Through this infrastructure, citizens are guaranteed access to medications specified on lists drafted by government administrators.⁶ These actions delegated responsibility but did not ensure sustainable funding and technical capacity at local levels. Medications are frequently out of stock and lists of newer high-cost medicines are infrequently updated (Campos 2007; Homedes and Ugalde 2005). A private health care system exists as well, but does not cover medicines, and many health providers participate in both systems.

AIDS activists were among the first to successfully equate the constitutional right to health with access to medicines (Scheffer, Salazar, and Grou 2005). And in 1996, during a time when global responses to HIV/AIDS were largely prevention-based, Brazil became the first developing country to sign into law and to enact a policy of free and universal distribution of antiretroviral drugs (ARVs). In the years that followed, Brazil has seen unprecedented alliances among activists, government reformers, multilateral agencies, and the pharmaceutical industry (Berkman et al. 2005; Galvão 2002; Gauri and Lieberman 2006; Okie 2006; Parker 2009; Scheffer et al. 2005). The country has asserted itself as an innovator and leader in the efforts to universalize access to expensive AIDS therapies through generic drug production, drug price negotiation and distribution, and South–South technology exchange programs. An incremental change in the concept of public health took place through the universal AIDS treatment policy (Biehl 2007). In terms of both delivery and demand, public health is now understood less as prevention and primary care and more as access to medicines and community-outsourced care; that is, public health has become increasingly pharmaceuticalized and privatized.

Treatment access is a central tenet of global health activism and interventions today (Adams, Novotny, and Leslie 2008; Brown, Cueto,

and Fee 2006). Public–private health initiatives are booming and pharmaceutical companies are also rebranding themselves as “global health companies,” making older treatments available and expediting access to newer ones. Some critics contend that public–private treatment partnerships can be used by corporations as a good public relations move, offsetting public scrutiny of the pharmaceutical industry’s political influence and the opaqueness of its drug-pricing practices (Applbaum 2010; Samsky 2011). Companies can also use partnerships to gain footholds in developing-country markets, to influence national drug policies, or to improve drug distribution networks.

Such is the case of Brazil. From a market perspective, it is once again the country of the future. The federal government has successfully juggled demands for market openness *and* poverty reduction: it has strategically withdrawn from strict market regulation and, while championing much needed social policies, it has consolidated itself as a strong state, way beyond the minimum neoliberal one. In 2009, Brazil’s GDP was \$1.796 trillion, and its GDP per capita was \$10,427, ranking 103rd in the world (World Bank 2009). In 2004 about 20 percent of the population lived below poverty line, a number that fell to 7 percent in 2009. Income inequality, as measured by the Gini coefficient, is one of the highest in the world but, according to the World Bank, it has been falling due to “low inflation, consistent economic growth, well-focused social programs, and a policy of real increases for the minimum wage” (World Bank 2009).

Today, a variety of actors—patient associations, industry advocates, and public health physicians—have vested interests in making high-technology medicine accessible to all. In the process, the country is becoming a profitable platform of global medicine. It is estimated that almost 50 percent of the adult population (about 60 million) uses pharmaceuticals continuously (Carvalho 2003). And this is where the state comes into picture: pharmaceutical access.

In a conversation about unequal drug pricing worldwide, a pharmaceutical executive suggested that his company was adapting to the human rights and social justice frameworks that had success-

fully politicized access to treatments and health care in the recent past. Referring, for example, to the ongoing struggle over continued access to state-of-the-art antiretroviral drugs in Brazil, he said rather bluntly that his company had co-opted the activist role. To make government act properly, he suggested, “You don’t need the activists; just buy our drugs and you will save money.” Yet, we know that drug prices in Brazil are 1.9 times higher than in Sweden and 13.1 times higher than world’s index (Nóbrega et al. 2007).

Brazil is now experiencing the types of problems and conflicts that other middle- and low-income countries treating AIDS will soon face. It has an inexpensive first line of ARVs, but a growing number of patients are starting new, more expensive drug regimens, either because of drug resistance or because newer medicines have fewer side effects. From 2004 to 2005, the cost of treating a single AIDS patient cost rose from \$1,220 to \$2,577, and the total cost of providing AIDS therapies more than doubled from \$193 million to \$414 million (Nunn 2009). In 2009, 32 different drugs were available in the Brazilian HIV/AIDS program: 59 percent of them (19 drugs) were imported, corresponding to 72 percent of the total spending).

State-purchased high-cost medicines now make up a formidable market in Brazil—from \$208 million in 2004 to \$377 million in 2005. In 2002, the Health Ministry spent more than \$1 billion on essential and high-cost drugs. In 2007, it spent about \$5 billion.⁷ Drug expenditures grew over 250 percent between 2002 and 2007 (Vieira 2009).

In the wake of the country’s highly publicized antiretroviral drug rollout, the rights-based demand for treatment access migrated to other diseases and patients. People of all social backgrounds are mobilizing for increased and sustained access to medicines that are either covered by government programs and are not available to them or to specialized treatments not provided by the government (these include treatments for prevalent as well as uncommon and rare disorders: from diabetes to bipolar disorder, asthma, hepatitis C, and rare genetic disorders such as MPS).

Ana Marcia Messeder and colleagues (2005) profiled this medico-judicial phenomenon in the state of Rio de Janeiro. The authors identified a total of 2,733 medicinal lawsuits filed between January 1991 and December 2002 and analyzed a representative sample of 389 of them. The majority of cases were initiated by public defenders or pro bono lawyers from nongovernmental organizations (NGOs) or universities, and only 16 percent of the lawsuits came from patients being treated outside of SUS. Until 1998, plaintiffs almost exclusively demanded medications for HIV/AIDS.

Messeder and colleagues found that beginning in 1999, however, two years into the universal AIDS treatment policy, there was significant diversification of the kinds of medications and pathologies to treat, including diabetes, cancer, and conditions other than HIV/AIDS, in court cases. As the cases diversified and the rights discourse and legal practices pioneered by AIDS patients and lawyers were adopted by people facing other diseases, the number of cases dramatically increased. In 1995, only four such cases were filed against the state of Rio de Janeiro. In 1997 this number had increased to 314, and in 2002 it was 1,144. While the users of these drugs “are exerting greater organizational and lobbying skills to secure their rights” (2005: 532), public defenders and judges lacked clarity about the division of pharmaceutical responsibility among various administrative levels. Indeed, they were found to show “disregard for the rational use of medicines and for possible harms that come with misprescription and misuse” (2005: 533).

These mostly poor patient-litigants were exhibiting knowledge and skill that their class position typically did not confer and were challenging public health administrations to fulfill their mandates. Although the public debate over judicialization has tended to focus on demands for experimental and high-cost medicines, the two published social scientific studies of right-to-health litigation (from the state of Rio de Janeiro; Pepe et al. 2010; and the municipality of São Paulo, Vieira, and Zucchi 2007) show that the majority of those cases requested medicines that were already part of governmental pharmaceutical distribu-

tion lists and about three quarters of the off-list medicines requested had a generic equivalent publicly available. This newer phenomenon—demanding access to treatments already on lists—could be an indicator of the failures of municipal administrations (the alleged providers) and state health secretariats (the supposed co-financers) to fulfill their public health duties.

While claims for pharmaceutical access have migrated well beyond HIV/AIDS and right-to-health litigation has become an alternative pathway for accessing health care in Brazil, a ruling by the Supreme Court in 2000 concerning a patient's access to a newer anti-retroviral drug still constitutes the precedent for judicial intervention in both state and federal courts. In his ruling, Justice Celso de Mello understands the AIDS pharmaceutical assistance program as the actualization of the government's constitutional duty to implement policies that secure the population's health. As the concrete embodiment of the need for "programmatic norms," the AIDS program acquires an inherent judicial value in his ruling. As soon as the needy citizens have medicines, according to Mello, the government's legal responsibility for implementing programmatic norms that secure health are fulfilled and cease to be "an inconsequential constitutional promise." In this rendering, the immediate assurance of the right to health through medicines circumvents questions about the limitations of policy and resources as well as the evidentiary basis of new drugs' efficacy.

Public health actors and institutions around the globe are currently struggling with how to guarantee the human right to health and fulfill promises for increased access to treatments while contending with the enduring limitations of public health paradigms and delivery systems. As the judicialization of the right to health grows in volume and importance in Brazil, it signifies a new chapter in the construction and management of the country's universal health-care system as well as its evolving pharmaceutical political economy—the eighth largest pharmaceutical market in the world (internal sales amounted to \$15 billion in 2009) (Sindicato das Indústrias Farmacêuticas do Estado de São Paulo 2009). Brazil's response to the judicialization of the right to

health is an important litmus test for other low- and middle-income countries where increased pharmaceutical access is under way.

RIGHT-TO-HEALTH LITIGATION

Young Rita's legal process, like that of the other patients receiving enzyme replacement therapy at the Hospital Universitário, remained unresolved. It had grown "to half a meter high," in the words of Mr. Moura, the lawyer who represented several of these families. For Mr. Moura, the litigation pathway is the only way possible because "the state does not fulfill its role. Health is the duty of the state and the right of the patient." He insists that in almost all cases, initial rulings are in favor of the patients. Genetic therapies are a new threshold in the judicialization of the right to health, he adds. Why? "Because these are medicines with a slightly elevated cost."

Brazilian states like Rio Grande do Sul are seeing the number of successful court cases reach the tens of thousands, redefining the roles and responsibilities of the state, altering administrative practices, and encroaching upon health budgets. With a population of 11 million people, Rio Grande do Sul is facing one of the greatest numbers of health-related lawsuits in the country (Hoffmann and Bentes 2008). There were over 12,000 lawsuits in the state seeking access to medicines in 2009 alone, a staggering increase from 1,126 in 2002. In 2008, the state spent \$30.2 million on court-mandated medicines. This expense represents 22 percent of the total state expenditure on medicines that year (Biehl et al. 2009).

Consider Lizete, who is suing the state for medication to treat her pulmonary hypertension. The 48-year-old woman lives with her husband, a taxi driver, in one of the shantytowns of Porto Alegre. Lizete found out she was HIV positive in 2002. Unlike the AIDS therapies she receives for free at the local health post, the drug that she urgently needed was not offered through the public system and would cost her about \$1,300 a month. On the doctor's advice, Lizete went to the Public Defender's Office, where she qualified for free legal representation, and sued the state. She initially lost her lawsuit but later won on appeal.

Although a judge ordered the state to begin immediate provision of the medication, when interviewed in August 2009, several months had past and Lizete had yet to receive the drug. She hoped to improve so that she could return to work and better care for her 11-year-old adopted son.

Past research has suggested that right-to-treatment litigation is a practice of the financially better off (Chieffi and Barata 2009; Da Silva and Terrazas 2008; Vieira and Zucchi 2007) and that low-income patients tend to sue for low-cost medicines while higher-income patients tend to sue for very expensive medicines (Da Silva and Terrazas 2008: 12). In contrast, an analysis of information collected from over a thousand medicinal lawsuits against the state of Rio Grande do Sul⁸ suggests that patients who procure medicines through the courts are mostly poor individuals who are not working and who depend on the public system for obtaining both health care and legal representation. Among the plaintiffs who reported their employment status, more than half were retired and about a fifth were unemployed. Among those who reported income, over half earned less than the monthly national minimum wage (about \$300) and relied on the free legal services of public defenders.

Roughly two-thirds of the medicines requested were already on government pharmaceutical distribution lists. About a quarter of lawsuits were exclusively for access to on-list, high-cost, medicines and low-cost essential medicines were frequently requested alongside other medicines. Off-list medicines requested by plaintiffs were also often low-cost and many had been available in the market for a long time. This suggests that government pharmaceutical programs are failing to fulfill their role of expanding access and rationalizing use (Decit 2006; Guimarães 2004).

Moreover, judges at a district and at the higher court levels almost universally granted access to all medicines requested, recognizing the provision of medicines as consistent with Brazil's constitutional right to health. For example, in almost all cases, district judges granted plaintiffs an immediate injunction for access to medicines; in cases where the initial ruling was in favor of the provision of medicines, the state higher court upheld the decision most of the time.

According to legal scholar David Fidler (2008), developments in health jurisprudence “have produced open-source anarchy and a more elastic relationship between power and ideas in global politics” (2008: 410). In such an elastic relationship, “changes in material capabilities of state and non-state actors, and changes in the world of ideas, have more impact on each other than in the closed, state-centric system that prevailed during the Cold War” (2008: 410). Fidler recognizes a “deeper importance for law in public health endeavors within and between countries” (2008: 394; see also Fidler 2007).

Anthropologists John and Jean Comaroff have been attending to such a “judicialization of politics” in postapartheid South Africa and how it has impacted social mobilization, particularly in the field of HIV/AIDS. Class struggles, they argue, “seem to have metamorphosed into class actions. Citizens, subjects, governments, and corporations litigate against one another, often at the intersection of tort law, human rights law, and the criminal law, in an ever mutating kaleidoscope of coalitions and cleavages” (2006: 26; see also Vianna and Burgos 2005; Yamin and Parra-Vera 2010).

Right-to-health litigation speaks to a productive “open-source anarchy” (Fidler 2008) at both macro and micro levels in Brazil as well. Interviews we conducted with judges, attorneys, and public health officials revealed divergent and conflicting views on the litigation pathway that, as we have been suggesting, has become an alternative pathway for accessing health care. Many judges working on right-to-health cases feel they are responding to state failures to provide needed medicines and that these waves of lawsuits are a milestone in the democratization of a culture of rights. Whether this goal can be attained through individual claims, however, is contested. The fact is that judges employ idiosyncratic rationales and create their own standards in adjudicating right-to-health cases. They tend to rule in terms of “risk of death” and “right to life” and base their rulings for the most part on constitutional interpretations and personal experiences—having specific tragic cases in mind.

Administrators contend that the judiciary is overstepping its role and that judicialization skews budgets and increases inequalities

in health care access. Some acknowledge, however, that legal pressure has improved the distribution of some medicines. In the meantime, private law offices specializing in medicinal lawsuits, such as Mr. Moura's, have spread and local public officials are capitalizing politically on such court cases, using them to gain media attention and popular support. Many patients are indeed poor and are represented in court by public defenders from the state's independent public defense office. The public defenders we interviewed see their work as a mode of guaranteeing accountability; they also seek greater visibility and political significance within state institutions. Patient associations play a highly contested role. Officials claim that at least some of them are funded by drug companies eager to sell the government high-cost medicines whose efficacy might be questionable and widespread prescription unwarranted.

Judicialization has indeed become a parallel infrastructure in which various public and private health actors and sectors come into contact, face off, and enact one-by-one rescue missions. In April 2009, the Brazilian Supreme Court held a rare public hearing to examine the pressing challenges posed by right-to-health litigation.⁹ Public health officials, lawyers, physicians, activists, and academics testified before the court, providing varied viewpoints and recommendations on how to respond to the enormous judicial demand for medical goods. As an immediate outcome, there was a long overdue updating of government pharmaceutical distribution lists. The Brazilian National Council of Justice also issued a set of recommendations for local judges, asking them to more systematically attend to scientific evidence and to strive for "more efficiency" when ruling over health-related cases.¹⁰

If access to AIDS therapies was the litmus test of the right to health in the 1990s, now it is access to genetic therapies. The latest right-to-health landmark ruling involves a request for a high-cost medicine for a genetic disease. This treatment was not recommended by the Ministry of Health's therapeutic guidelines and was not publicly available. In March 2010, the court rejected the argument that the state was not responsible and decided in favor of the provision of the treat-

ment. In his ruling, Justice Gilmar Mendes stated that once the disease was confirmed and evidence was provided that the treatment was indicated, the “Ministry of Health’s therapeutic guidelines are not unquestionable.” Moreover, “the state has to provide resources, not only to support and fund the provision of the universal care for its citizens, but also has to provide variable resources to attend to the needs of each individual citizen.”

There is a heated debate in Brazilian courts on the positive duty the constitutional right to health imposes on the state and extent to which the courts must enforce this right. But the country has yet to have a substantial public debate about the meaning of the right to health in light of medical advancements and financing, between what is possible and feasible. The government, in fact, remains reluctant to create a bolder regulatory apparatus around technology assessment and drug pricing. Larger questions of health systems reform and the social determinants of health remain unexplored. Meanwhile, hard to pin down patients-citizens-consumers draw from human rights language and jurisprudence and make governments resourceful as they negotiate medical inclusion and the vagaries of the market and survival.

The ways and means of right-to-health litigation reveal an intense political-economic-experiential field: here the absolutization of neoliberal market principles in health-care delivery goes hand-in-hand with a surprising absolutization of the juridical subject of rights. The rational-choice-making economic subject is also the subject of rights. This dual subject position complicates Michel Foucault’s concept of biopower—how natural life has been taken as an object of modern politics (1980; 2007). In judicialization we do not see a top-down biopolitical model of governance in which population well-being is the object of knowledge and control but rather a struggle over the utility of government by multiple private and public stakeholders. There is an economic reason within governance.¹¹ At stake here are the ways in which government (as drug regulator, purchaser, and distributor) facilitates a more direct relationship of atomized subjects of rights/interests to the biomed-

cal market in the form of technology access alongside the continual creation of commercial horizons.

PATIENT-CITIZEN-CONSUMER

Rita has a “severe case” of MPS, Dr. Maria told us. “She walked until she was four,” her mother, Ilse, added. “She even went to nursery school but now her whole body is damaged. The organs, liver, and spleen have enlarged and she also has respiratory problems.” Ilse insisted that Rita improved while in the clinical trial, but that she also knew that the enzyme does not “stop the neurological damage.” Later Dr. Maria told us that she believed that Rita’s disease was too far along with neurological damage for the enzyme to be effective. Yet all parents we spoke to suggested that not obtaining this treatment (whose access they had to renew periodically in the courts) would be unconscionable or tantamount to killing their children.

Dr. Daniel Muller, who coordinates MPS trials at Hospital Universitário, does not see high-tech treatments for MPS as magic bullets. “They can stabilize the disease,” he told us, “or maybe lead to small improvements.” He also spoke of the need to a more effective “community genetics”: “We have tools to go to the community and to work preventively at the level of prenatal screening and early care of the child.” While new genetics diagnostics are being disseminated in the public health-care system, doctors cannot offer termination of pregnancy as an option, he added, “given this predominantly Catholic country’s anti-abortion laws.”

The therapeutic imperative voiced by the families we spoke to—“we would do anything and go anywhere to get the treatment”—is indeed embedded in a complex medical-legal-religious context, a “conservative continental problem” in Dr. Muller’s words. To complicate matters further, the family’s affective tissue has become an entry point for a grassroots and somewhat troubling uptake of high-tech treatments. According to Dr. Muller, many families make “emotional rather than rational” decisions: “Even though we have clinical scales to differentiate between severe, intermediate, or mild forms of the disease that

can help us to decide which cases should or should not be treated . . . today, with judicialization, treatment depends on the family and on the judge's understanding. If we don't give the family a prescription they can go to another doctor."

The initial MPS clinical trials in which Rita participated tested the efficacy of the enzyme on older children and young adults. Now approved and in the market, new trials are testing the enzyme for safe use in younger children. The study that Dr. Muller coordinates at Hospital Universitário has attracted 12 new families from all over Brazil and also from Chile and Bolivia, he told us.

Whether such trials are public goods or exploitative mechanisms is a complicated matter (Petryna 2009). Pharmaceutical companies are increasingly enlisting public specialized treatment centers in middle-income countries, such as the genetics service at Hospital Universitário, to run trials. These centers have highly qualified staff and the capability of recruiting specific patient pools. For example, there are some 600 diagnosed MPS 6 patients globally and a quarter of them live in Brazil. Be it Brazil, Poland or Taiwan, as trials unfold and evidence is produced, they also morph into powerful marketing tools as multiple stakeholders struggle to make the treatment standard via a protocol and reimbursable by insurance companies in the United States or by the government as in judicialized Brazil.

Ilse stated that taking care of Rita is "my work, full time." Her second husband, Rita's father, is the breadwinner. After discovering the girl's condition and wanting to avoid "the 75 percent chance of having another MPS child," the couple adopted a son. He brings "joy to the house," Ilse said. The parents want the courts to grant the treatment for Rita's "whole life" (*vida inteira*). The mother continued, "She will not be cured of MPS 1. There is no cure. But she needs the enzyme." For her, the therapeutic imperative is not a push for cure but an effort to keep Rita alive. Arguably, here the biopolitics of the state rests in access to technology or not and "making live and letting die" has become a familial affair. "The state should give it to her. It's stressful to have a sick child and to have to fight for her to get the medicine which she

has a right to. It is Rita's right as a Brazilian citizen. But we must always fight with judges, prosecutors. . . . It is so exhausting. This is my work, day and night."

Mirta and her two children with MPS 6 come from the rural town of Fronteira. Her first child "had it too, but she died at the age of three. She would be 22 years old now. There was no treatment at the time." When asked their age, Jessica mumbled a number to which the mother said *mais alto*, louder. "TEN." Pedro was eight. Their infusion had just ended and both watched cartoons on TV.

"It is a struggle," Mirta said, conveying how her family had to learn to operate simultaneously as subject of rights and interests in this therapeutic state-market complex. "Every week we leave Fronteira at 1:30 a.m. The city hall transports us by van. We get here at 6:30 a.m. and when the infusion ends we return home." Mirta's husband manages garbage collection for the town. "Jessica walks, but Pedro walks very little. They go to school in the afternoon." When asked what she does for a living, Mirta plainly states, "I take care of them." We had heard that these children having difficulties accessing the ERT. "Yes," Mirta said, "we have to sue all the time."

For years, Jessica and Pedro had been coming to the service for clinical observation and palliative care. When a study was launched to test the enzyme replacement therapy, "They did not meet the age criteria of 6 and above," Mirta lamented. She interpreted this exclusion in constitutional terms: "They did not have *the right to be researched*." Excluded, the family kept a close eye on the MPS study. Once it was published and the drug was approved by ANVISA to be sold in Brazil, "The doctors called us and asked if we wanted to *entrar na justiça* to see whether we could get it. Of course, we said 'yes.' The doctors and the MPS association are in constant contact with us."

There is no pre-given biopolitical population to which these atomized subjects of rights belong. Yet, in their private efforts to become such subjects, these children and guardians have to rely on temporary collectivities such as patient associations that crop up at the intersection of patient/family demand, pharmaceutical marketing, and

legal activism. Mirta was thankful for the lawyer who the “MPS association hired for us” but she did not recall his name or the terms in which Jessica and Pedro’s cases were argued before judges who were ruling on their claims for treatment. She did not have a clear sense of how to act in her scripted subject position and lamented constant uncertainties and court fights in renewing access to the ERT. “Jessica got the treatment for ninety days and Pedro for forty days. Their cases never fall into the hands of the same judge.”

TECHNOLOGY ACCESS AND PRIVATIZED HEALTH

Continuity of treatment weighs heavily on doctors who place their patients in trials for new genetic therapies or who prescribe these therapies. Several of the doctors we interviewed mentioned that when studies end, trial sponsors can provide the drug for some time, either as part of an extended access or compassionate use program. “But all this is at the company’s discretion.” Dr. Maria emphasized that these children’s biologies are misshapen by treatment discontinuity: “Sometimes they get it, sometimes they don’t.” Pedro and Jessica suffer from a “complete lack of consistency” of access of medication.

Not only are these children’s biologies precariously tethered to new medical commodities, but the timing of rulings and court injunctions unleash their own kinds of hazards. “Patients go for some time without the treatment until a court injunction comes,” Dr. Maria told us. Doctors provide crucial means of veridiction to patient’s legal claims for treatment, but the courts themselves become battlefields of veridiction–falsification, as the state’s general attorney’s office has created a task force of medical consultants to verify or disqualify claims for treatment access and efficacy.

Conflicts over evidence in courts create their own set of medical problems. According to Dr. Maria, “It is worse to have the treatment and stop it than to not have it. When treatment is interrupted and then restarted when a new ruling or injunction comes, patients almost always have an adverse reaction to the medication. The protein in the therapy is foreign to their bodies. In the medical reports we file

as part of the lawsuit we try to make the case that treatment should not be interrupted but we know that this argument does not necessarily work.”

How does the celebrated economic equation “more technology equals better health outcomes” square with the on-the-ground reality of judicialization? (Cutler and McClellan 2001; Cluter, Deaton, and Lleras-Muney 2006) A major challenge facing clinicians such as Dr. Maria and colleagues is how to assess whether the enzyme is actually improving the patient’s condition. Even in the therapy’s postmarketing stage, patients remain in a kind of experimental state. “What does the treatment actually improve in the patient? They have had the disease for a very long time, eight or nine years, and have had very little treatment time. We know that the enzyme improves lung function. But in terms of the other markers, we need more time to really assess the effect of the enzyme.” The one-by-one judicialization of access to new medical technologies also opens up an additional tenuous space between treatment and research, a tenuousness that might well be replaced by standardized regimens in the future. But we wondered to what extent parents were aware of this experimentality in the bodies of their “children-litigants.” How can we facilitate a more informed public debate about the uncertainties of the science, effectiveness, and true costs of therapeutic advancements?

Parents at this clinical unit had crafted informal measures of the effectiveness of the therapies and they used them to index the negative biological impact of the legal odyssey the family navigated. Mirta, for example, mentioned her children’s increasing alertness and dexterity as well as hair softening: “We know that this ongoing litigation is not good for the children’s health. I can see the difference. When Jessica and Pedro don’t have the medicine, they are compromised. They should take it continuously.” As families push through courts and legal paperwork, their “biotechnical embrace” (DelVecchio Good 2007) strengthens and the questionable efficacy that the doctors delivering the ERT are aware of is less and less an object of concern. When all goes well in this makeshift drug delivery system, Mirta added, “The judge stamps

our claim and we ourselves get the money and give it to the hospital which in turn buys the enzyme. The treatment costs 18,000 dollars per month, 36,000 dollars for both of them. It is a lot, right?”

Not even siblings with the same disease like Pedro and Daniela constitute a legitimate collective in this privatized and malleable right-to-health enterprise. Dr. Maria underscored a sense of medico-judicial confusion: “One of the most difficult realities we face is that judges give different rulings for each MPS patient. But here we have the case of two siblings who have MPS 6. They have different judges and each one gives treatment for different time periods.” According to Mr. Moura, at the moment this is actually the best legal strategy: “I am against collective lawsuits. Each MPS patient is unique and takes different dosages, for example, and their particularities might play against them if it were a collective case.” For him, individual lawsuits could potentially circumvent the close scrutiny of expert committee reviews and state prosecutors’ appeals aimed at “postponing treatment more and more.” Arguably, the state and its legal actors are putting into circulation epistemic collectives derived from an evidence-based medicine. These virtual collectives (standing for a knowable population of needs that is no more) clash with the subject positions composed by desperate patients and families and their temporary medical-legal and activist networks.

Pedro and Daniela did not have the right to clinical research, but they did have their constitutional right to health. As their mother put it: “They should get the medicine *pra vida inteira* [for the whole life] so that we would not have to always activate the justice, *pouco a pouco* [little by little].”

The family had a sense that their struggle would only become more intense as right-to-health jurisprudence was evolving unpredictably. The state’s highest court had just recently ruled in favor of the government and held an MPS drug manufacturer responsible for the treatment costs of a child who had been in a clinical trial. State attorneys requested and the court mandated that the manufacturer should provide the patient with free treatment for life, even if this was not

stipulated in the informed consent. To justify the decision, the State High Court wrote that “it is unacceptable for the manufacturer to use human beings as ‘guinea pigs’ in its studies and then leave people who were of vital importance helpless to obtain an extraordinarily expensive product, especially when health improvements were observed and patient expectations were raised” (Tribunal de Justiça do Estado do Rio Grande do Sul 2009).

CODA

With the global expansion of biomedical markets and their encroachment in public health-care systems we see a recasting of the role of neoliberal government. In the Brazilian case, the market finds utility in the government as drug purchaser and distributor and in specific mobilized communities. These communities, cast as therapeutic market segments, use lawmaking and jurisprudence to be seen by the state and make it act biopolitically. Government is thus geared less toward population health as a means of achieving productivity and control and more toward facilitating or triaging the relationship of subjects of interests (framed as rights) to the biomedical market in the form of technology access.

People’s life chances and health outcomes are overdetermined by what kind of market and juridical subjects they are able to become by appealing to the judiciary and government as well as to research and health industries. We have to attend to forms of statecraft (national and regional) and jurisprudence as well as the political subjectivities that are built into this new apparatus of interests and rights, the possibilities opened up, and the exclusionary dynamics at work in Brazil and elsewhere. Thus, from the perspective of judicialization, health in the time of “global health” is a painstaking work in progress by monadic juridical subjects in relation to therapeutic markets, ailing public health infrastructures, and fragile medical collectives.

This essay pointed to the fragility of biopolitical interventions, showing how they are constantly entangled with and shaped by other

(often economic) imperatives. The stories of patient-litigants and their families also point to the power of biotechnology to remake human and social worlds as it opens up new spaces of ethical problematization, desire, and political belonging. It is at the intersection of the therapeutic imperative, the biotechnical embrace, and the reason of the market that the intensity of survival becomes visible.

NOTES

1. See “O Abecedário de Gilles Deleuze” <<http://www.oestrangeiro.net/esquizoanalise/67-o-abecedario-de-gilles-deleuze>>.
2. Except in cases where individuals chose to be identified, we maintained their anonymity to the extent possible by using pseudonyms. We also changed the names of institutions.
3. In discussing the pharmaceuticalization of health care and the judicialization of the right to health in Brazil, we draw from Biehl’s *Will Live: AIDS Therapies and the Politics of Survival* (2007) and Petryna’s *When Experiments Travel: Clinical Trials and the Global Search for Human Subjects* (2009). We also draw from a multidisciplinary study on right-to-health litigation that is under way in southern Brazil and that is coordinated by Biehl.
4. The first MPS treatment was approved by the FDA in 2003 (laronidase for MPS I), followed by two other drugs approved in 2005 (galsulfase for MPS 6) and 2006 (idursulfase, for MPS 2). These drugs were approved by ANVISA in Brazil in 2006, 2009, and 2008, respectively.
5. The 1983 U.S. Orphan Drug Act provides incentives for the development of drugs to treat rare diseases affecting “fewer than 200,000 persons in the U.S.” or “more than 200,000 persons in the U.S. but for which there is no reasonable expectation that the cost of developing and making available in the US a drug for such disease or condition will be recovered from sales in the US of such drug.” These incentives include tax credits for clinical research and seven years of market exclusivity for an FDA-approved drug.
6. The federal government has acquired high-cost medicines in exceptional circumstances since the 1970s, but only in 1993 was an offi-

cial program for acquisition of these high-cost medicines (*Programa de Medicamentos Excepcionais*) created (Ministry of Health 2010a). The federal government ceded the administrative responsibility of this program to state health secretariats, but without a well-defined co-financing mechanism. Although many drugs were included in the program's initial pharmaceutical distribution lists, only a few were effectively distributed to the population, due to erratic and irregular acquisition and distribution processes (Souza 2001). In 2002, the exceptional medicines program was extended to include 92 drugs and more precise criteria were formulated to inform their distribution (Souza 2001). Finally, in 2006 the Ministry of Health issued a ministerial decree (Portaria GM n° 2577 de 27 de outubro de 2006) outlining the specific objectives and responsibilities of the states and the federal government in regard to the exceptional medicines program (Ministry of Health 2010). Currently, 110 therapeutic products (including medicines, biological products, and nutritional formulas) are included in the program, which is now called "Specialized Component of Pharmaceutical Assistance" (Ministry of Health 2010b).

7. In 2007, four drugs were responsible for 28 percent of the Health Ministry's drug expenditures: imiglucerase, epoetin alpha, human immune-globulin, and interferon alpha-2b.
8. This specific study was carried out with Dr. Paulo Picon and other scholars, including Joseph J. Amon, Mariana P. Socal, Rodrigo S. Gonzalez, and Claudio D. Terra, among others. The study was financed by the Ford Foundation and Princeton University's Health Grand Challenges Initiative and it was supported by the Secretaria Estadual da Saúde do Rio Grande do Sul, the Procuradoria Geral do Estado do Rio Grande do Sul, and the Fundação Médica do Rio Grande do Sul. The information mentioned here was discussed in a workshop at the Escola Superior da Magistratura da AJURIS, Porto Alegre, August 2009, and it was publicly presented in a seminar at the Tribunal Regional Federal da 4a. Região in Porto Alegre on September 29, 2009.

9. For a detailed review of the public hearing, see <<http://www.stf.jus.br/portal/cms/verTexto.asp?servico=processoAudienciaPublicaSaude>>.
10. In 2010, the Brazilian National Council of Justice issued a recommendation for judges to always verify at the National Commission of Research Ethics (Comissão Nacional de Ética em Pesquisas, CONEP) if the requested drug was “part of experimental research programs” of the pharmaceutical industry and that, in that case, judges should mandate these industries to assume treatment continuity. (Recomendação nº 31, de 30 de março de 2010. DJ-e nº 61/2010, em 07/04/2010, p. 4–6 <http://www.cnj.jus.br/index.php?option=com_content&view=article&id=10547:recomendacao-no-31-de-30-de-marco-de-2010&catid=60:recomendas-do-conselho&Itemid=515>).
11. In his 1978–1979 lectures at the Collège de France, Foucault argued that we can adequately analyze biopolitics only when we understand the economic reason within government reason: “Inasmuch as it enables production, need, supply, demand, value, and price, etcetera, to be linked together through exchange, the market constitutes a site of veridiction, I mean a site of veridiction-falsification for governmental practice. Consequently, the market determines that good government is no longer simply government that functions according to justice” (2008: 32).

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Susie Orbach

Losing Bodies

IT COULD BE SAID THAT MEDIA HAS A GREAT DEAL TO ANSWER FOR when it comes to how we understand our bodies today. Information, disinformation, commercial practices, and crazes arrive through the media. It is the medium that stimulates public conversation and trends. It is the means by which the individual finds out things and is impacted by them. Even those of us who feel ourselves to be outside of or perhaps critical of the impact of media are rarely unaffected.

Think of the food we eat now and how it is prepared and presented compared to 25 years ago. How did that update occur? Think of the furniture in our homes and the ways in which we have wanted to refresh or renovate the look of our abodes. Think of going into a restaurant and there being an A-list movie star at the next table. She or he becomes compelling not because of his or her art per se but because visual culture and the publicity machine creates the notion of a star, which then works on us.

Something outside of us—film, print, photo, magazine, newspaper, TV—magnifies the object. It is hard to escape. It enters us, and then our interest in that object becomes part of who we are, entwined with our sense of self and community, an aspect of our identity as crucial as church iconography was several centuries ago.

We don't like to think of ourselves as beguiled by this beast called the media. We like to think of ourselves as agents with the force to act and make an impact. And of course we do. We can see this energy very clearly through social media, which has quasi-democratized the possibility of having a voice. But there is no straightforward relationship

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between “us” and the media, no clear divide that has an uncontaminated “us.” The us that we are is not created in isolation. The us that we are and the way we perceive of our bodies are the outcome of the intimate relationship that we make with the world around us.

When we try to tease apart the outside and the inside it becomes quite difficult. The thoughts and pictures we carry inside of us express this complexity. Take for example the compelling desire of many young Western women to have labiaplasty. It doesn’t help the young woman to say: what you see projected in the media as a labia is not *the* labia. Your labia is meant to look the way it does. Or rather it doesn’t help much. She doesn’t feel that to be so. She feels ashamed of the way the folds of skin come together. She’s been having a Brazilian wax since she first got pubic hair. For her that was an entry point into grown-up femininity and it pleased her and confirmed her membership in that identity. But not quite.

The Brazilian wax has been a prelude to the disgust and plan to reshape her labia, her breasts, and her buttocks. These are now the procedures she will undergo to find some body peace.

We could just call it body hatred. We could call it fashion. We could call it psychopathology. We could call it opportunistic medical greed. If we compare female genital surgery (FGS) to a practice we find unethical, female genital mutilation (FGM), and link these first world practices to those we condemn elsewhere, we take pause. We ask whether the way in which a neoliberal agenda has designated the female body, either purposefully or unintentionally, as the site for transformation, control, and profit is being delivered to us through the media’s exhortation for us to reshape our bodies? We ask how have consumption and the notion of choice, two exhortations of late capitalism, combined with the imperative to reconstruct and perfect the body through visual media?

In 1995, a television channel started broadcasting in Fiji. It showed imported U.S. shows, such as *Friends*. By 1998, a mere three years later, 11.9 percent of Fijian adolescent girls were over the toilet bowl with bulimia, where previously none existed.

These young women had identified modernity with the Westernized body shape of the last few decades and they had embraced it. In their attempt to find a place in global culture, they understood that the reshaping of their body was crucial. The idea—reshape the body—was an outside one but it insinuated itself into their own longings and desires. They didn't experience themselves as having been done over by the media and—this is an important point—they didn't feel themselves the passive recipients of a rapacious and controlling media. They felt themselves rather, to be in dialogue with what was being presented (Becker 1995). Like women in so many locations in the world, they felt excited and interested. They perceived the way they were to be radically out of date and in need of upgrade. *The site of modernity for them became the reconstruction of their bodies.*

In Shanghai, a fashionable operation is to break the thigh and extend the leg by 10 centimeters. In Singapore, the latest craze is for the Western nose. In Eastern Europe, thin has become a requisite for the young wishing to enter global culture. In South Korea, 50 percent of teenage girls have the double eyelid slit operation to Westernize the look of the eyelid. Cosmetic surgery, whether on visible body parts or the more intimate genital area, has become a serious growth industry.¹ The Singapore government has funded a center to attract cosmetic surgery tourism. In Argentina, those with health insurance have the right to a cosmetic procedure annually or biannually. Those without health care coverage can buy their new breasts and have them inserted in the public hospital. So deep and so pervasive is the sense that our bodies are not okay as they are that private organizations see profitable opportunities while state organizations see obligations toward their citizenry. This is shown most dramatically in the West as government bodies regulate and measure children and adults on the basis of a spurious statistical whim, the Body Mass Index (BMI) (Oliver 2005). Those of us over 40 did not grow up with this measure but with weight charts divided into small-, medium-, and large-framed. Today, health economics has been captivated and captured by a measure of weight and height that, despite being contested by the National Institutes of Health (Flegel

2005), has come to hold sway among health professionals. They decree what is an acceptable body and they then provide contracts to diet companies to regulate the unacceptable. The diet industry, already highly successful through a combination of factors around size acceptability, fear of food, societal panic about "obesity," and the industry's high recidivism and subsequent repeat customers (Orbach 1978), is now being bloated by government funds.

The populace is instructed on how to manage media-generated cues on eating that are propagated by a food distribution industry in search of greater numbers of products with longer shelf life that can lure customers by another section of the food industry: the diet companies. An unvirtuous circle pertains. Heinz owns Weight Watchers, Unilever owns Slimfast, Nestlé owns Lean Cuisine. Questions that relate to internal body prompts such as hunger and satiety are virtually invisible. Those cues do not generate excess profits. They may even create contented bodies. But this latter experience is rapidly becoming foreign as the parents of 6- and 7-year-olds are warned about the implications of their child's BMI.

What kind of conception do we have of the body? Can we speak in any sense of a normal body or is it more accurate to say that what is at stake today, especially for the young—young women and young men—is the acquisition of a body "normalized" by visual dictate: a body whose dimensions, whose look, is not simply stylized but homogenized; a body created by the style industries (the beauty, cosmetic, fashion, media, celebrity industries) that is then reshaped by the cosmetic surgeons, the gym instructors, and diet industries.

You may protest bodies were always shaped, normalized by cultural forces. There is no such thing as a body not marked or shaped by culture. To be unmarked, as in uncircumcised, for example, is to be unclaimed and unclaimable. The body is marked by gender, by class, by nationality, ethnicity, by custom. The body as natural, as unmediated, is a bucolic, naïve Rousseauian fiction. Romantic notions efface the impact of contemporary culture without being able to erase culture at all, for this is an impossibility.

We look at the history of the world as we understand it through the costumes, clothing, and physical stance of its people—from the ancient Babylonian togas to the Masai warrior markings to the Victorian crinolines. Even the Wild Child of Aveyron grew in a context—it wasn't a human context—so his body was formed in proximity to the animals and he developed the sensibilities suitable for his environment. His body temperature self-regulated to cope with snow or sunshine without the clothing we find so necessary. He moved in ways similar to the animals he grew up with. And so on. Every body requires a context. There is no such thing as “a body.” There is only a body as an outcome of relationship. And that relationship is always culturally situated (Orbach 1986, 2009).

Our bodies are given to us by our mothers (Orbach 1978). They do this in two ways: by the bodies they themselves inhabit and represent to us, and also through how they perceive our own bodies' capacities; introduce us to our bodies' wonders; constrict, enable or shape our bodies in ways relevant to the cultural context, with nary a conscious thought for doing so. A Jewish or Muslim boy is circumcised; a girl, too, in certain Muslim traditions. Deep in the Amazonian forest in Brazil, the Kaiapo Indian children absorb their way of kissing which, to our way of interpreting physical gesture, is a bite. The behaviors are enacted as part of the ordinary social matrix of relating. There is some specific instruction, such as when I was a girl, which related to sitting with my legs together or being told not to whistle because it wasn't ladylike, but there was nothing particularly forced about such instructions; they were the medium in which femininity in the United Kingdom from my class background was formed. There was a specificity to that body that meant that when another encountered it, it could be read as the body of a girl from or aspiring to a particular milieu.

What is markedly different today is that mothers' bodies are under assault. There is no stable body for a woman. There is no milieu that has constancy. The body is being reshaped by visual culture in literally thousands of presentations weekly we receive through television, magazines, newspapers, digital media, and advertising. No one can count the images accurately. The advertising agencies, whose income depended upon

knowing such things, said 5,000 a week, but that was before the Internet and social media took off and images were propagated on screens continually.

What is remarkable is the homogeneity of the images broadcast internationally. At the Hayward Gallery six years ago, a photographer took pictures of individual models and melded them one to another. The morphed image could have been anyone of them. They were—they are—all super-slim and tall with features that can be painted out so that new ones can be painted on. As models and celebrity culture infuse public space, indeed become a form of discourse, so the images of femininity (and it is happening with masculinity, too) become ever more reduced and uniform.

Pascal Danguin, the artistic retoucher, routinely remakes pictures. In the March 2008 issue of U.S. *Vogue*, for example, he changed 144 images (Collins 2008). Meanwhile, some obstetricians have been prepared to allow women to follow the example of movie stars and celebrities who proclaim the virtue of caesarean sections at eight months for the spurious cosmetic purpose regaining their pre-pregnancy bodies by six weeks postpartum. The notion of a full-term pregnancy, with women learning their baby's rhythm and that of their own, is becoming endangered, with grave consequences for their bodily sense of self and their internal, body-based knowledge of appetite and satisfaction. One day they will have a chance to be the maids of honor who are offered cosmetic surgery a year before the wedding to complement the bride they are serving. Body insecurity will have insured a lack of corporeal confidence, and the imperative to shape up, to reconstruct—not only to aspire to but to physically enact bodily alteration—will speak to them.

What does all this mean?

One thing it means is that the body of the mother as experienced by the baby may well be one marked by anxiety (Orbach 1995). Another thing it means is that the anxiety the baby absorbs prepares her or him for a sense that a body does not exist as a place to live from but as something one needs to be ever watchful of and tending to. As a

toddler, the little girl sees this explicitly. She hears her mother sigh at her own body in front of the mirror or hears her berate herself for “indulging” in foods. The child may not know what any of this means but it is the medium in which her own relationship to her body develops. The mother may Photoshop the baby’s or toddler’s photos, inserting a dimple or a cute gap between the teeth, in a facsimile of what a baby, toddler, child is to look like. Neither the body of the mother nor the body of the child is deemed good enough as they are. Panasonic’s 2011 camera, the Luminex FX77, can whiten teeth, magnify eyes, and add makeup. The bodies and faces of mothers and babies are both being “perfected.” The child is being unwittingly prepared for the combined blandishments of the beauty, style, food, and diet industries, whose greed knows no bounds and in whose wake the cultural diversity of bodies all over the world are eaten up. The person grows up thinking/believing that bodies are inevitably unstable and always in need of attention and transformation.

The individual body is the outcome of that most intimate of relationships between the mothering person and her child as she personally enacts the cultural dictates vis-à-vis the body. At this moment in history, those personal enactments include the reshaping of the body, with the most unfortunate consequence of creating body distress and body hatred.

Indeed, one of the West’s hidden exports to the developing world is body reshaping and its concomitant rejection of the local body. We are losing bodies faster than we are losing languages. Women from all over the world shed their local body as they enter modernity, whether from Nigeria, Ladak, or Kosovo. The formerly plump tradition for beauty queens in Nigeria has been superseded by a Westernized thin shape. The first slim Miss Nigeria (chosen by eyes dominated by Western cultural imagery) was initially assumed to have HIV/AIDS, but rapidly her body spurned a Nigerian diet industry. The female body, reshaped as thin and preferably long, has become the insignia of belonging. It is not the clothes that brand the body but the honed body as brand itself; the sign that one has shed one’s indigenous culture and taken up the world body.

We are losing bodies as we are losing mother tongues. Commercial pressures disseminated through the media are restructuring bodies, supplanting diversity with sameness and offering membership in global culture through having a body that fits. These bodies become the calling card of identity and belonging, while supplying gargantuan profits to the industries that breed body hatred. Globalization as a modern form of imperialism reshapes not just the architecture, industry, and agriculture of the external world, but the private, corporeal space we endeavor to inhabit. Corporeal colonialism is a hidden glue that links in with colonial histories of the past.

NOTES

1. The seriousness of the situation has been recognized by the Vienna city government, which has produced guidelines on female genital surgery. See <www.frauengesundheit-wein.at>.

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