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## GOOD GIFTS FOR THE COMMON GOOD: Blood and Bioethics in the Market of Genetic Research

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### Abstract

This article is based on ethnographic fieldwork conducted with the Indian community in Houston, as part of a NIH–NHGRI-sponsored ethics study and sample collection initiative entitled “Indian and Hindu Perspectives on Genetic Variation Research.” At the heart of this research is one central exchange—blood samples donated for genetic research—that draws both the Indian community and a community of researchers into an encounter with bioethics. I consider the meanings that come to be associated with blood donation as it passes through various hands, agendas, and associated ethical filters on its way to the lab bench: how and why blood is solicited, how the giving and taking of blood is rationalized, how blood as material substance is alienated, processed, documented, and made available for the promised ends of basic science research. Examining corporeal substances and asking what sorts of gifts and problems these represent, I argue, sheds some light on two imbricated tensions expressed by a community of Indians, on the one hand, and of geneticists and basic science researchers, on the other hand: that gifts ought to be free (but are not), and that science ought to be pure (but is not). In this article, I explore how experiences of bioethics are variously shaped by the histories and habits of Indic giving, prior sample collection controversies, commitments to “good science” and the common “good of humanity,” and negotiations of the sites where research findings circulate.

### Keywords

blood donation; gift exchange; genetics research; bioethics; community consultation; India; Indian community in Houston; International HapMap Project

### ONE: FRAMES

After being subjected to ethnocide and genocide for 500 years (which is why we are endangered), the alternative is for our DNA to be collected and stored. This is just a more sophisticated version of how the remains of our ancestors are collected and stored in museums and scientific institutions.

Why don't they address the causes of our being endangered instead of spending \$20 million for five years to collect and store us in cold laboratories. If this money will be used instead to provide us basic social services and promote our rights as indigenous peoples, then our biodiversity will be protected.

<sup>53</sup>*Editor's Note: Cultural Anthropology* has published a range of articles on the cultural dimensions of genetics. See, for example, Michael J. Montoya's "Bioethnic Conscription: Genes, Race, and Mexicana/o Ethnicity in Diabetes Research" (2007); Karen-Sue Taussig's "Bovine Abominations: Genetic Culture and Politics in the Netherlands" (2004); and Corinne P. Hayden's "Gender, Genetics, and Generation: Reformulating Biology in Lesbian Kinship" (1995).

<sup>54</sup>*Cultural Anthropology* has also published several articles on diaspora and diasporic identity, much of which builds on James Clifford's "Diasporas" (1994). Other examples include Brian Keith Axel's "The Context of Diaspora" (2004) and Jacqueline Nassy Brown's "Black Liverpool, Black America, and the Gendering of Diasporic Space" (1998).

—Tauli-Corpuz, 1993

In the Mahabharata, a story is told of the great warrior Karna's encounter with Indra, king of the Gods. Karna's kavacha and kundala [armor and earrings], gifts with which he was born and which were for that indistinguishable from his body, made him undefeatable in battle. Realizing this, Indra decided to approach Karna in the guise of a Brahmin beggar at just that hour in the day when Karna refused no favors. Surya, Karna's father, who had bestowed these protective gifts upon his son, appeared in a dream the night before to warn Karna of Indra's plan. But Karna would not refuse the Brahmin begging for alms, so he tore armor and earrings from his skin, giving of his very body to the stranger who came and asked.

The first of the two "frames" given above is by now a familiar refrain from critiques of the Human Genome Diversity Project, an international initiative to collect blood samples from select indigenous communities to anchor understandings of human evolution (see Textbox 1). The passage is excerpted from testimony provided by Victoria Tauli-Corpuz, then representative of the Cordillera People's Alliance in the Philippines, at a 1993 meeting of the UN Commission on Sustainable Development. Although valuing the idea of a global commons in which "indigenous knowledge and biodiversity" could be stored and shared, Tauli-Corpuz voiced serious concerns over the Human Genome Diversity Project and called for the project to be halted.

The second is a story that was repeated to me on a few different occasions in the course of fieldwork among (East) Indians (hereafter, "Indian") in Houston, conducted as part of a larger project to understand Indian perspectives on genetic variation research. This was a "community consultation" project sponsored by the ELSI (Ethical, Legal and Social Issues in genomic research) program of the National Institutes of Health and the National Human Genome Research Institute (NIH-NHGRI), which sought to engage the Indian community in Houston on questions of genetic research, and ultimately to collect 140 blood samples from Indian Gujaratis for the construction of a Haplotype Map: a strategized cataloguing of human genetic variation (see Textbox 2).<sup>1</sup> To this end, it was part of my charge as an ethnographer to conceptualize what the act of blood donation might mean to Indians resident in Houston, and what sorts of ethical questions the proposition to donate for genetic research might posit. Essentially, then, the NIH-NHGRI community consultation project asked Indians both for a donation to research and about the meanings of that contribution in the (imagined or real) act of giving.

**Human Genome Diversity Project (HGDP);**

**<http://www.stanford.edu/group/morrinst/hgdp.html>** The HGDP is an effort of anthropologists, geneticists, doctors, linguists and others to "document the genetic variation of the human species world-wide," conceived as a critical complement to the Human Genome Project in the early 1990s. Samples were to be collected from approximately 500 populations worldwide (with the aim to expand that number), with consents to participate obtained by either knowledgeable local informants or anthropologists. The HDGP promised insights into populations' "history and origins" as well as more medically oriented

<sup>1</sup>The ELSI Research Program was started in 1990 as part of the Human Genome Project, to foster research on the ethical, legal, and social implications of genetics and genomic research for individuals and communities. The program is funded by three to five percent of the annual Human Genome Program budgets of the NIH and DOE (U.S. Department of Energy) and is currently administered by the NHGRI. As such, it represents one of the largest bioethics initiatives in the world. Anthropologists have frequently been involved in ELSI community consultation research, and have been part of a large number of the consultations undertaken as part of the HapMap project (see Textbox 2)—although several may argue that their roles as ethnographers have been reduced and instrumentalized in the process. Even so, the opening up of ELSI funding has made "ethics" a virtual bridge between the natural and human sciences (Marcus 2002). Our project in Houston was perhaps unique in its emphasis on ethnography prior to sample collection, all the more given the participation of three anthropologists in the research group (see Reddy n.d.).

knowledge about diseases and therapies. Its diffuse focus in combination with sampling strategies that identified populations as “isolates of historical interest,” among a host of other issues, soon invited vocal criticism from indigenous communities, anthropologists, geneticists, and others. The building controversy eventually resulted in the shutting down of the project by the end of the decade.

**International HapMap Project (<http://www.hapmap.org>)** The International HapMap Project is a collaboration among scientists in Japan, China, Nigeria, the United Kingdom, and the United States, formally launched in 2002. Its goal is to create a haplotype map of the human genome, to describe common patterns of human DNA sequence variation. Differences in individual bases of the DNA sequence are called single nucleotide polymorphisms (SNPs or “snips”). Sets of nearby SNPs on the same chromosome tend to be inherited in blocks, and their pattern on this inherited block is known as a haplotype. Blocks may contain large numbers of SNPs, but only a few “tag SNPs” are sufficient to uniquely identify haplotypes in a block. Such reasoning makes it possible to reduce the number of SNPs needed to examine the entire genome to 500,000 tag-SNPs from 10 million common SNPs. Genome scans that seek to find genes that affect diseases will therefore become both more cost-effective and efficient.

The International HapMap Project itself does not attempt to correlate genetic variants with diseases, but to make information about variation available to other researchers who may then carry out disease-specific research programs.

The HapMap was initially compiled from four sets of samples collected internationally and named thus to indicate their sources: Yoruba in Ibadan, Nigeria; Japanese in Tokyo, Japan; Han Chinese in Beijing, China; and CEPH (Utah Residents with ancestry in Northern and Western Europe). To these originary four were to be added a longer list that included samples from African Americans in Oklahoma; the Luhya in Webuye, Kenya; Communities of Mexican origin in Los Angeles; Denver (Colorado) metropolitan Chinese community; Toscani in Italia (Tuscans in Sesto Fiorentino, Italy); and, finally, Gujarati Indians in Houston, Texas. (Many of these sample collection initiatives have been preceded by a period of community consultation.) The relationship between the different data-gathering phases of the HapMap project is not entirely clear; in fact, the HapMap was announced to be complete in October 2005, more than a year ahead of the scheduled completion of our research in Houston. Samples collected after 2005 are supplements to the existing HapMap, at best. All samples are stored at and distributed from the Coriell Institute in Camden, New Jersey.

Although these narratives and the others they suggest are, in many ways, quite incognizant of one another, they represent nonetheless two broad frames of reference for the present article. The Indian characterization of blood donation does not reproduce the rhetorics of vampirism, biopiracy, and racism invoked by HGDP critics, as shall be seen. Quite the contrary, Indians seem generally to laud and promote blood donation as a form of community service appropriate to an age of rapid and necessary technoscientific progress. And yet, the political history of (human) sample collection itself, in particular the legacy of the HGDP and continued scientific initiatives to study human genetic diversity in the form of the International HapMap Project, feeds into the very framing of the assignment to study Indian views on genetics. Were it not for prior controversies, in other words, the question of ethnographically engaging the Indian community—or the Mexican American, Chinese, African American, Yoruba, Luhya, or other communities engaged in the successive phases of the HapMap Project—prior to sample collection would likely not have arisen as it did. As strikingly apolitical as the Indian community’s responses to the subject of genetic research appear to be, these exist within an overtly political frame that perforce cannot be set aside for its dissimilarity.

How, then, do these two apparently divergent rhetorics, the one less culturally particular than the other; the one more overtly political than the other; the one deeply critical of science, the other cheering on work in the name of science— intersect and interact in the course of ethnographic research? In the sections that follow, I chart a movement between these frames of reference as donors (from “the community”) and recipients (researchers from the scientific community), by their positioning within the ELSI bioethics project, bring disparate contexts into articulation. For the “community” represented by a regionally and culturally diverse group of Indians in Houston, blood is largely and unproblematically a possession but a wholly alienable one to be freely given for an easily identifiable “greater good.”<sup>2</sup> For a community of researchers, particularly bioethicists and those others allied with bioethics initiatives (incl. anthropologists and geneticists), blood is an abstract but ethical problem, one that marks out a terrain fraught with anxiety, the perpetual threat of controversy, and all the attendant legal–institutional protections and precautions. To navigate the interactions of these frames, I draw on a model of coproduction borrowed from science studies and ask: What is the relationship between “Indian perspectives on genetic variation research” and the wider context within which such studies exist?<sup>3</sup> How are these frames articulated, and what other frames do they set in motion? How are local engagements inflected by controversies far beyond their immediate environments—and vice versa?

There are, I argue, fundamental tensions between blood as moral nonissue and blood as ethical and political dilemma, blood as individual gift and blood as abstraction for research ends, and blood as contribution for community benefit and blood as intellectual property. And yet, there is also a discernible consonance between Indian views and HapMap goals on the uses of blood for the promised outcomes of genetic research. Here are shared ideas of “good science” and shared valuations of the promises of genomics, both of which become evident precisely as a result of the interaction of the divergent ideas, histories, frustrations, adaptations, and wishes that constitute the frames of this research. As a result, blood becomes less, rather than more, controversial as it moves from veins to vials and from one framework to others. Here is equally an instance of a controversy anticipated but averted, a controversy that could have happened but did not, a motion that progressed almost counterintuitively, apparently without friction (Tsing 2005). There ought to be very little aside from pure relief to report, but I suggest otherwise: there is, rather, an elaborate narrative about a cultural encounter with bioethics to be read from this instance of a dispute averted. The “awkward, uneven, unstable, and creative” interactions “across difference” that comprise this encounter are at the heart of what the present article seeks to document and delineate (Tsing 2005:4).

The discussion below begins much as I began my ethnographic engagement: rooted in the Indian community and amidst Indian imaginaries, finding myself needing to synthesize and explain genetics to Indians, and “Indian perspectives” on genetics to a community of scholars (bioethicists, geneticists, and others involved in the social study of the human genome) as part of the ELSI–HapMap community consultation process. The process began within our research group, which included a bioethicist (PI), a physical–medical anthropologist, a project manager

<sup>2</sup>Although our charge in this project was to collect samples from “Gujarati Indians,” our two-year ethnographic engagement was not limited to people originally from Gujarat State in India. Quite the contrary, we reasoned that because the scientific insights produced from Gujarati blood samples would no doubt be applied to all Indians (and possibly also to South Asians), Indians representing different religious, regional, and community perspectives needed to be consulted for their views. The ethnographic material presented in this article, therefore, is based on conversations with a broad cross-section of the community. As it happened, however, most of our interlocutors are long-time Houston residents, and have had at least some significant years of education in India.

<sup>3</sup>In science studies, the idiom of coproduction stresses “the production of mutually supporting forms of knowledge and forms of life” (Jasanoff 1996:397; for other works that exemplify such an approach see Ezrahi 1990; Jasanoff 2004; Latour 1990; Reardon 2001 and 2004b; Shapin and Schaeffer 1989). This article draws rather more on an adaptation of this premise for ethnographies of science: Paul Brodwin’s (2006) suggestion that the distinction between the moral (as purview of anthropological discourse) and the ethical (as elite bioethics discourse) has outlived its value, and that a theory of coproduction that emphasizes the “interconnectedness of social orders” (Merry 1992:358) would be better suited to understanding the interactions of these two terrains.

(also a cultural anthropologist), and me as the only Indian and Indianist in the group.<sup>4</sup> From this position within a larger collaborative enterprise, I became acutely aware of what I presented above as the frames of this research: the differences between the “Indian cultural” and “bioethical” narratives that our study brought into conversation, and the ways in which Indian cultural perspectives were drawn into an extended encounter with bioethics.

In the sections below, I explore this encounter as it unfolds, stage by stage. How is blood transacted in this encounter with bioethics? What sociohistorical meanings and contexts are “conscripted” to biogenetic substance as it moves from veins to vials and the abstract research terrains beyond (Montoya 2007)? The encounter with bioethics produces goods to be exchanged (blood, cell lines, data, or scientific innovation), which themselves generate theories of the good (ethical research, ethical exchange, or universal benefits). And yet the paths to these goods remain quite distinct: encounters with bioethics are variously modulated for the various participants in the research exchange. In sum, the exchange of blood for research precipitates a qualitatively distinct bioethics at each stage of the transaction—and the many pieces of that transaction bear closer examination to understand fully how bioethics is made and remade, experienced and reexperienced along the way.

## TWO: THINKING IN TERMS OF GIFTS

In a richly provocative rereading of Mauss’s *Essai sur le Don*, Jonathan Parry offers the following insight: “while Mauss is generally represented as telling us how *in fact* the gift is *never* free, what I think he is really telling us is how *we* have acquired a *theory* that it should be” (Parry 1986:458). I take the “we” of Parry’s statement, drawn directly from Mauss, to refer to the Western or Christian world, or, perhaps more accurately, to the societies shaped by “ethical salvation religions” in which things of this world, being “antithetical to a person’s true self,” are likely to foster “the separation of persons from things ... an ideological precondition for market exchange” (Parry 1986:468). That it was the Christian world that developed theories of “pure utility” and disinterested giving, Mauss indicates and Parry concurs, is no accident. And further, such theories are in fact two sides of the same coin: pure utility and the attendant logics of market exchange develop hand-in-hand with “*universalistic* conception[s] of purely disinterested exchange” and the push to philanthropy. In reverse as Parry states it, “the ideology of the pure gift may thus itself promote and entrench the ideological elaboration of a domain in which self-interest rules supreme” (Parry 1986:486, 487). Given that such separation is peculiar to a “certain type of society,” Parry’s argument draws attention to contexts in which the question of the pure gift does not even arise because the distinctions inherent in the idea are simply not made. Particularly, he focuses on the concept of *dānadharma*, loosely translated as the law of religious giving, in India.<sup>5</sup>

In my work among Indians in Houston, I have been struck by how often a particular kind of gift, the donation of blood for the purposes of genetic research, is applauded and justified in the name of “the community,” “the good of humanity,” “the greater good,” and even more generally, “a good cause.”<sup>6</sup> “What is the use of my blood if I cut myself and bleed on the table?” an elderly (Muslim woman) physician expressed genuine surprise at my questions about ownership, identification, and the rationale for donation to research causes. “If my blood was lying here it wouldn’t produce any results,” she continued later, “I would just get a cloth and wipe it up. But when researchers study it, they contribute other things to it ... in the process

<sup>4</sup>For more on the predicament of ethnography within such collaborative enterprise, see Reddy n.d.

<sup>5</sup>Parry is careful to note that *dāna* represents but one mode of Indic giving. *Dāna* is thus to be viewed in relation to other modes of giving: *bhiksha* (alms), or *dakshina* (offering of one’s wealth, particularly to a guru), for instance. *Dāna* can itself take multiple forms: for example, *go dāna* (giving away cows), *anna dāna* (giving away food), *kanya dāna* (giving away of daughters in marriage), *bhu dāna* (giving away land). Contemporary extensions of the term to the giving away of blood (*rakt-dāna*) indicate the mutability of this form of giving. My interlocutors translated the concept simply as “donation,” interweaving social and religious obligations, as I show.

the donation serves a greater good.” More often, interlocutors would explain their support of blood donation to research despite potential risks with the simple insistence that “it will be for the good of all,” or that “humanity will benefit from the Knowledge, whatever the outcomes.” At the second of our sample-collection drives, a gentleman associated with the BAPS [Bochasanwasi Shri Akshar Purushottam] Swaminarayan temple (whose booth happened to be adjacent to ours) virtually took it on himself to send prospective sample donors our way. His enthusiasm for our study on the grounds that it would undoubtedly “benefit everybody in the community” and his success in attracting donors with that simple enticement rendered our carefully crafted, IRB-approved Informed Consent documents fairly irrelevant. Collective benefit was clearly what was at stake here, far more than the agency of individual donors.

Throughout fieldwork, the concept of the “larger good” remained almost wholly an abstraction; in their conviction that Knowledge, no matter how troubling, would always be useful, my Indian interlocutors never fully explained how it could be useful, or what specific good it would serve. Neither did they really share our need for precision in this matter: when pressed, one focus-group participant at the Arya Samaj of Greater Houston pointed out that the task of defining the good (or its opposite) was an impossible one because “you [researchers] say yourself that we do not yet know what all research on the genome could uncover.” Interlocutors’ concern with the risks and harms of genetic research varied, but the distinct possibility that genomic research would serve the “good of humanity” handily outweighed the possibilities that it would do otherwise.<sup>7</sup>

What are we to make of such apparent commitment to sketchy, abstract, seemingly ill-defined conceptions of the good? Rather than dismiss these Indian views as evidence of a lack of sufficient thought given to the issues surrounding genetics, I read them as a generalized expression of bioethical thinking and a contemporary elaboration of the theory that Parry derives from Mauss: gifts are not usually free, but they certainly ought to be. This implies a continuing tension between the mutually constitutive pulls of interested and disinterested exchange. The picture is complicated, however, by the fact that Indian gestures often invoke the term *dāna*—here loosely translated as “donation” with more-or-less religious underpinnings, but still a concept that apparently obviates the distinction between interest and disinterest in exchange. *Dāna*, however, does not so much replace as it coexists with other, sometimes contradictory, modalities of giving, so the notions of an ostensibly pure or free gift selflessly given “for the greater good” and the opposite it implies linger nonetheless.

Here, then, is another complication: what constitutes a “free gift” in this instance seems quite apart from anything Mauss, or indeed Parry, may have intended. *Free* here means not so much pure as unencumbered, and more importantly freely available to all: “for the good of humanity.” In this second sense, it contains an idea of property akin to that of the “commons,” in which the gift is given to nobody in particular, but is held in common for the good of all. This, I dare suggest, is a contemporary translation of the gift as *dāna*. In its classic form, *dāna* contains the giver, takes careful stock of recipients, but then is wholly alienated in the act of giving. When invoked for general “good causes,” by contrast, it becomes something less uniformly dependent on personhood, not just for the greater good but for a particular good that circulates in the context of market relations.<sup>8</sup> The donation, then, is simultaneously a free gift that transcends

<sup>6</sup>Others have noted an emergent commitment to give in the interests of “society” or the greater “public good” in pre-Independence India. Douglas Haynes (1987), for example, traces the historical circumstances under which particular forms of gifts (tributes) gave way to more generalized philanthropy reflecting concern for the “public good” under colonial rule (see also Watt 2005). Jacob Copeman writes further of a (postcolonial) shift from “conventional modes of giving—money to temples, food to the dead, the staging of feasts and so on” to an “emergent imperative to give that which will be useful ... for an ‘in need’ society,” where “society” is defined somewhat cursorily as an entity apart from family life “to which useful things should be contributed” (2007:53–54).

<sup>7</sup>In fact, interlocutors regarded some risks as benefits of a kind: the physician quoted above remarked that “even if you find that I belong to a group that has lower intelligence, then at least I can know, and I can find out what to do about it.” Others echoed her views in very similar terms.

the interested and disinterested exchanges of the market and a free gift that seeks precisely to circumvent the pressures of market–model exchange. This transformation of *dāna* perhaps necessitates a further rewriting of Parry’s insight above: although we (larger “we” here, “we” in the marketplace) understand that goods are never free, indeed cannot be, we have perhaps acquired a theory that some ought to be. Looking at gifts of the body, asking what sorts of gifts these are, and how they are requested and their giving is rationalized sheds some light on the means by which this underlying theory comes into being.

### THREE: BLOOD HISTORIES IN THE BIOETHICAL ENCOUNTER

The habits of bodily giving in India have been shaped considerably by the need for donation to blood banks, to sell or donate to specific people in need, and also somewhat infamously by the traffic in organs such as hearts, livers, and particularly kidneys. This history of giving the body then influences the ways in which Indians encounter and experience bioethics—as a product of a particular historical tension between sale and gift, and between market model exchange and its posed alternatives. From 1942, when the first public blood bank was established in India, to 1967, the norm was to collect blood from professional, paid donors. A 1967 campaign spearheaded by the International Red Cross and the Government of India brought the concept of voluntary, nonremunerated blood donation into existence. It was not until 1996, however, that the Indian Supreme Court decided to ban blood collection from professional, paid donors, illegalizing paid donations, and thereby also fostering the emergence of new mechanisms for paid donations in the form of “replacement blood” (Viczyany 2001:387).<sup>9</sup>

Lawrence Cohen writes also of the Transplantation of Human Organs Act (THOA), passed in 1994 in the face of scandals in which physicians were accused of tricking people into giving up kidneys, which illegalized solid-organ sale, but provided for “exceptions” that then have become the new mechanisms for (paradoxically) legitimizing organ sales and even avoiding state audits and criminal prosecution (2005:80–81). “Love” becomes the mediating force in such reformulated transactions: the enacted pretense of love to help a recipient in need, the refusal to accept the sacrifice of a kidney (or blood) from a loved one, and the seller’s erased love for those whose needs may have prompted the decision to undergo a nephrectomy in the first place (Cohen 2005). The underlying logic of sacrifice may grease monetary transactions or be inverted in such transactions, but as Parry points out in the Hindu context (citing the laws of Manu), “the gift is a kind of sacrifice ... is in fact a surrogate for sacrifice appropriate to our degenerate age” (1986:460). Much the same might be said about blood officially donated as “replacement” but privately compensated, with the acknowledgement that the comparison of blood to kidney is a limited one.

In drawing attention to this background, I mean to point also to the imbrication of sale with gift (with sacrifice), not merely to their opposition. But the fact that there are laws banning paid blood collection and solid-organ sales gives the opposition of sale to gift a new existence in the form of volunteerism. India’s National Blood Policy calls for a launching of “extensive awareness programmes for donor information, education, motivation, recruitment and retention in order to ensure adequate availability of safe blood”—a directive that the director of the Jeevan Blood Bank and Research Center in Chennai then understands as a need to create a “a culture of donation ... the culture of helping somebody” in a rolled together recognition–awareness–empowerment campaign to D.R.E.A.M. (Donor Recognition Empowerment

<sup>8</sup>The use of the word *good* in the rest of this article invariably indexes this dual meaning.

<sup>9</sup>*Replacement blood* refers to blood collected from family members of someone who may have received a transfusion, so as to replenish the available blood supply. Viczyany tells us, however, that families under pressure to donate replacement blood may be tempted to turn to paid donors rather than family members in times of need, thus extending the practice of paid donation under the guise of replacement donations (2001:387).

Awareness Management).<sup>10</sup> *Blood Must Circulate*, insists Jeevan, overlaying the physical body onto the body politic. The culture of volunteerism becomes one to be created by “caring people,” “people who dare to dream differently, the people who think beyond the bread & butter, the people who think themselves as the ‘citizens of the world.’”<sup>11</sup> It is driven above all by “social commitment” and the need to connect “those with a heart and those who need a life.”<sup>12</sup> Love is a mediating force here, too, but in an altered sense of identification with a larger, less personal, humanity: “The love of fellow human [*sic*] and a desire to share something of oneself is what singles out a blood donor from the others.”<sup>13</sup>

Caring People, an NGO in Moradabad, draws inspiration from the Sanskrit saying *vasudaiva kutumbakam* [the whole world is one family], to reject boundaries and espouse nothing short of “the cause of humanity.”<sup>14</sup> Extricated from the face-to-face contexts of a sale (of blood or organs), the ideal donor becomes one whose “primary motivation is to help unknown recipients,”<sup>15</sup> a “citizen of the world” with the ethical responsibility to the countless unknown “some-bodies” (*some-bodies*) who might be in need of blood.<sup>16</sup> Ethical responsibility now provides a depersonalized context by which donations to unknown others acquire meaning. Giving blood becomes a form of SUPW, as Indians know it in school, Socially Useful Productive Work, community service perhaps more than donation, a particular reformulation of the social contract that then produces particular ethical imaginaries (Simpson 2004:841).<sup>17</sup> The unknown stranger in need, the “life” uncontextualized except by its medical need (and medical need is the mitigating factor, else we are commonly taught to mistrust strangers) is the figure who mobilizes an ethic of generalized caring and social responsibility, precisely by its anonymity. The anonymity of the figure could be read as an appeal to respond to social suffering in abstract form, but its deliberately decontextualized generalizability nonetheless also begs the question—ethical responsibility to what?

Jacob Copeman responds by examining Indian political rituals of blood collection, in which camps are organized and blood given through the elaboration of the metaphor of nationalism (2004). The deaths of nationalist figures such as Bhagat Singh, hanged by the British for bombing the Central Assembly building in 1929, are transmuted into blood sacrifices for the country to be acknowledged by further donations of blood. Indira Gandhi’s oddly premonitory statements about living and dying just before her assassination in November 1984 and her specific allusion to blood—“I can say that each drop of my blood will keep India alive, will make India strong”—then become material to encourage blood donation in her name and in the name of the cause (India) she represented in those final moments of her life (Copeman 2004:132). Even the names and images of regional film stars whose popularity rivals that of politicians and saints in India are harnessed to make the case for voluntary donation. And then, beyond the realm of the specifically political, “socio-spiritual” organizations such as BAPS *Swaminarayan Sanstha* routinely organize blood camps to mark the centenary and bicentenary celebrations of the various saints associated with the temple, festivals of various kinds, and also as part of the routine functioning of the institution—all to encourage people to take “time out of their busy schedule to give a piece of themselves to help a stranger.”<sup>18</sup>

<sup>10</sup>See <http://www.hinduonnet.com/thehindu/2001/07/31/stories/0431401y.htm> (this and all further URLs cited in footnotes were last accessed on March 7, 2007).

<sup>11</sup>See <http://www.blooddonations.org>; <http://www.blooddonations.org/about-us.html>, sic. So also is Khushroo Poacha of “<http://indianblooddonors.com>” impelled to harness the power of e-commerce for the purposes of establishing a “real-time” donor registry to make blood readily available during personal and national emergencies: <http://www.indianblooddonors.com/inthepress.asp>.

<sup>12</sup>See <http://www.bharatbloodbank.com>.

<sup>13</sup>See <http://bloodbanksdelhi.com/content/WhyDonateBlood.htm>.

<sup>14</sup>See <http://www.blooddonations.org/about-us.html>.

<sup>15</sup>See <http://www.iitd.ernet.in/new/blooddonation.pdf>.

<sup>16</sup>See <http://www.blooddonations.org/about-us.html>.

<sup>17</sup>Consider in such light the campaign of college students in Thanjavur, which has been successful in reducing the need for replacement blood: <http://www.hindu.com/2005/11/15/stories/2005111506220300.htm>.



Extricated from the face-to-face contexts of a sale (of blood or organs), inserted into a social welfare model that presumes distance between helped and helper (Titmuss 1997:283), donors are immersed in a world full of strangers characterized as potential recipients. The question “who is my stranger?” has perhaps no place in this discourse of giving, as Titmuss avers, but it is there nonetheless, and addressed nonetheless in the arguments and personifications deployed to elicit donations: the image of the wronged Bhagat Singh, the assassinated Gandhi family, the saints who establish such “socio-spiritual” institutions as BAPS. Giving here is minor sacrifice at best, but in this it pays homage to the sacrifices of others and to the notion of sacrifice itself. Blood becomes good by virtue of this association, but is simultaneously a transacted good given to ensure that India does stay strong and that BAPS continues its work in the world, just as the saints would have wished.

#### FOUR: BROKERAGE IN THE BIOETHICAL ENCOUNTER

Although the rhetoric of social marketing would have us identify with other citizens of the world and care for complete strangers, with perhaps only the tenuous promise that someday a stranger might similarly care for *you*, my point is that in practice there are no complete strangers and really no disinterested gifts. There is, instead, always a transaction mediated variously by saints, beloved political figures, or more concrete exchanges for extra marks in exams,<sup>19</sup> and free audiences at the Tirupati Tirumala Devasthanam (a temple thronged by thousands daily)<sup>20</sup>: the incentives given to grease the nonmonetary exchange, as it were.

The figure and role of the mediator interests me particularly, as it strikes me that negotiations of bioethics would be endlessly stalled without such middlemen. For here are brokered transactions in which the ultimate recipient, being almost wholly an abstraction, matters less than the person doing the asking on his or her behalf, and the tropes deployed to make the request compelling and meaningful. Arthur Kleinman makes a distinction between moral processes and ethical discourse, in which the moral is a dimension of practical, localized engagements with specific social worlds, and the ethical is abstract, principle based, a debate over codified values, the space of (bio)ethics itself (Kleinman 1998:363–365). The brokered transaction, in my view, occupies the space in between these modes: it is where the local–moral meets the abstract–ethical as it were, mingling, however fleetingly, to produce the decisive moment of exchange. The level of engagement with the ethical is not uniform across transactions; there is a clear difference between a blood donation made for the promise of extra marks, say, and one made with only the acknowledgement of a *tilak* (ritual mark placed on the devotee’s forehead) of earth collected from the site of Bhagat Singh’s cremation. But the complete stranger makes cameo appearance nonetheless, and then just as quickly fades.

In the HapMap work in Houston, I have been surprised, although I ought not to have been, to find myself being written into the position of broker. “Why would I donate blood?” one interlocutor asked, answering his own question thus: “Because you seem like a nice Indian woman, and you’ve come all this way to talk to us, so if you asked I’d give it.” Others pointed out more and less politely that it was not so much their responsibility as mine, as researcher involved with the project and as researcher doing the asking, to ensure that the donations were not misused and that community interests were protected. We are giving to you, the message seemed to be; the rest is your responsibility.

The strangers in question here, the recipients of the blood collected, are of a different order, it is worth stressing. This is blood given not for therapeutic treatment to identifiable persons in

<sup>18</sup>See <http://www.bapsicare.org/services/medical/bloodcamps.htm>. See also:

<http://www.tribuneindia.com/2004/20041016/nation.htm#15> for a similar example.

<sup>19</sup>See <http://www.hinduonnet.com/thehindu/2003/08/15/stories/2003081501660500.htm>.

<sup>20</sup>See <http://www.indianexpress.com/res/web/pfe/ie/daily/19980812/22450484.html>.

need nor even for specifiable disease programs, but for genetic research: abstract, idealized, basic science research whose promises are large, but the outcomes of which seem anything but clear, easily translatable for lay audiences, or predictable. The strangers are geneticists, biomedical researchers, and scientists: that is, types of individuals, each one by themselves also middlemen in the transactional chain, with the ultimate products of research being, by definition, public goods for the common good. Abstractions loom large over all conversations, become the very language of communication; the ethical transmogrifies into formidable terrain.

But when it comes time to actually donate, a wholly different mediating language takes over. It mattered then that we were researchers associated with Baylor College of Medicine, an institution of considerable repute to which, it should be added, a good many Indian daughters and sons go for their medical training—and that, in itself, was enough to justify the giving of a few tablespoons of blood, never mind its uses beyond the abstract specification “research.” It mattered next that the project budget had provided for some compensation for each sample collected, either to individual donors or to “the community,” loosely defined. And as the lines to donate for our advertised “Research study blood drive” grew longer and faster than we ever anticipated, I had to wonder if donors knew to what it was they were consenting: giving blood for genetic research (inherently defined as “good,” despite the “risks”; all abstractions anyway) that might benefit Indians years later, or giving \$50 per sample to the temple on whose grounds we were and by whose leave we were there in the first place, or, indeed, whether it mattered which consent was primary at all.<sup>21</sup>

I saw a priest who had participated in one of the discussions we held at the temple months earlier and approached him to offer greetings. “So you are collecting blood this time?” he asked. I replied that we were, and that despite the lack of resistance to our work, a certain wariness about proceeding to this phase of the research remained with me. He waved his arm, dismissing my fear graciously. “Don’t worry. We talk about ethics and all. But really it is for the good of everybody.” (He did not know at the time about the compensation to the temple for each sample collected). Others would later thank me for the opportunity to participate thus in “some community service.” The concept of the “good” in this instance indexes a disjuncture between the grand abstractions of ethics and the individual good deeds of community service at hand. And as blood from veins turns into “samples” in numbered tubes, and individuals become “subjects”—a source of persistent confusion on consent documents, where people will frequently write out the project title on the signature line marked for “research subject”—a series of strangers (phlebotomists, geneticists, and ethics itself) make cameo appearance and then fade. Prestation is exchanged for prestation, and all are happy that the greater good, less and more abstract, temple donation, and the imagined outcomes of “research,” but each one commonly claimed, has been served.

## FIVE: “COMMUNITIES” IN THE BIOETHICAL ENCOUNTER

All available samples collected, all consents obtained, we are packing up in the quietened florescence of the temple grounds. I am counting the samples in tubes, inadvertently touching the rubber seals. “I wouldn’t do that,” my colleague reminds me, being far more familiar with phlebotomies than I. The tubes are to be placed in some very elaborate packaging, boxes within foam within boxes to reduce the risk of breakage en route; they are to be shipped to the Coriell Institute in Camden, New Jersey, site of the National Institute for General Medical Sciences (NIGMS, part of NIH) Human Genetic Cell Repository, where immortalized cell lines will eventually be generated and made available to researchers requesting the HapMap samples, for a nominal cost to cover shipping only.<sup>22</sup> We have not marked the gender of each sample

<sup>21</sup>See Hayden 2003 for a similar instance of negotiating short-term, immediate returns, with the abstract promises of long-term returns in ethnobotanical bioprospecting contracts.

on the tubes, someone realizes. We have been meticulous about recording gender on consent documents for the purposes of demographic tracking, but there is no way to connect the consent documents to the samples themselves, of course, by writing gender information onto the tubes after the fact. Researchers using the cells will themselves test for gender, it is concluded; that is easy enough and standard research protocol besides.

The people have left the temple grounds, leaving their blood to turn to samples, in other words. They are now the problem of the researchers to whose care they have been entrusted. But what sort of a problem are these samples? And how are the issues presented by the samples to be resolved? Clearly it is not the moment of sample collection alone that produces the problem of blood; the problem of blood has defined the very framework of our study by giving us a methodology known as “community consultation”: a seemingly self-explanatory bundle of techniques by which “communities” are variously informed, involved, educated, consulted, or otherwise engaged in the research process, thereby bringing researchers and members of communities into dialogue.

A full history of how “community consultation” becomes key to ELSI research protocols and itself a key mediator of encounters with bioethics deserves more attention than I can undertake here. Suffice it to say that the idea of engaging communities gains force, and spurs further debate, as a consequence of pressing demands for group and collective recognition, sovereignty and identity, which “transform the context and substance of population genetics research” and in this “help define what the ‘principled conduct of research’ might mean in practice” (Brodwin 2005:148). In this charged political context, geneticists celebrate a milestone in the mapping of the human genome, our common genetic code, and refocus anew on groups, via population-based studies of human genetic variation. Announcements of the completion of the Human Genome Project mark the “start of an exciting new era ... of the genome in medicine and health,” in which possibilities “for investigating the genetic bases of human disease and drug response” are greatly enhanced by “incorporat[ing] information about genetic variation into human genetic studies.”<sup>23</sup> The International HapMap Project is highlighted among the new tools and technologies developed to render the genome navigable for medical research, specifically given its potential to produce a “detailed understanding of the heritable variation in the human genome” “at an unprecedented level of precision.”<sup>24</sup> In this, emphasis shifts already from the human genome as “the common thread that connects us all” into the need for a “comprehensive understanding of genetic variation.”<sup>25</sup>

The task of further studying genetic information that is now tagged to groups then quickly shores up the notion of collective risk in both biological and cultural terms: for a disease or for increased social stigma. Because the risks posed by genetic research are never exclusively biological, writers argue that it warrants community review, quite simply on the logic that members of communities may be better equipped to identify the “culturally specific risks” relevant to their lives (Foster et al. 1999:1720). Participatory research models have themselves been central in international development settings and also to health research, especially among minority communities (Macaulay et al. 1999). Feeding into this ongoing trend seeking to increase the role of “communities” in identifying health concerns and risks, community review gains stature both for its practicality and the added “moral value” of “assuring appropriate human subjects’ protections for genetic research” (Foster et al. 1999:1720).

<sup>22</sup>Because normal cells cannot proliferate indefinitely in culture, they are “immortalized,” often with the aid of viral proteins that inactivate specific tumor suppressor genes that tightly control cell survival and growth. Immortalized cells then retain the genotype and tissue markers of the normal cells they were derived from, but, unlike normal cells, they grow indefinitely and can be studied over long periods of time.

<sup>23</sup>See <http://www.genome.gov/11006929> and Collins et al. 2003:839.

<sup>24</sup>See Collins et al. 2003:839 and <http://www.genome.gov/11006944>.

<sup>25</sup>See <http://www.genome.gov/11006944> and Collins et al. 2003:839; see also Sandra Soo-Jin Lee et al. 2001:36.

At the same time, however, “community consultation” is heavily interrogated by a range of scholars who variously call attention to the problems of mapping social identifications onto such research categories as “populations” (Juengst 1998a), question notions of risks and harms (Reilly 1998) or the promise of better protections as a result of consultation (Juengst 1998b), and generally finesse the conceptual tools deployed in engaging communities over the issue of genetic research (Juengst 2000; Sharp and Foster 2000).

Critiques and skepticisms notwithstanding, the very basic and quite possibly self-evident premise of community review, that communities have a crucial stake in their futures and in their representations and therefore need to be at least aware of and ideally involved in research that involves them, remains intact. This premise, it bears reiterating, is put so firmly in place largely as a result of several prior encounters between researchers and community, particularly the debate over the HDGP, in which individuals and indigenous groups came to forcefully insist on the political underpinnings of scientific enterprise. Being themselves sample donors or among those targeted for sample collection, these groups demand a role in defining research agendas and interpreting the facts, and the right to accrue the (monetary) benefits of research itself. The overwhelming response to the HGDP was a particular consolidation of this critique, a globalized iteration of the politics of recognition that rendered Human Population Genetics forever “politically vulnerable,” as Paul Brodwin remarks (2005:148, 169), from that point on. The premise of community review, I mean to highlight therefore, is a particular response to this deepening sense of political vulnerability. On one obvious level it poses the question of what constitutes principled research, but in that it also brings into being, via such modes as community review, a particular conception of “ethics” and “ethical research practice”—a reformulation of the “E” in ELSI, if you will—to which I find myself heir on the grounds of the temple in Houston.

The problem of the good, then, from this perspective is first the problem of good (ethical, sound) research practice. The critique precipitated by the HDGP effectively accomplishes what even the egregious violations of WWII failed to tie up: it precludes science, scientific knowledge, and scientific endeavor from making straightforward claims to democratic representation. In this, it also partially shifts the energies of researchers from crafting “science” to drafting “ethics,” as one HGDP organizer put it (Reardon 2001:371–372). One indication of this shift may be found in the response of HGDP organizers to the wide criticisms of their work via the proposed “Model Ethical Protocol” (MEP) for the collection of DNA samples (North American Regional Committee 1997; cf. Reardon 2001:372). The MEP’s “core ethical procedure,” as Brodwin writes, is limited to a “transformed version of informed consent,” which “requires that researchers obtain the consent of *both individuals and groups* via their ‘culturally appropriate authorities’ before sampling a given population” (2005:155, emphasis added). So defining a “core ethical task” then generates an “ad-hoc sociology” that specifies the shape and structure of communities and “tailor-make[s]” social categories such that researchers may track the appropriate “chains of consent” (Brodwin 2005:155; see also Reardon 2001:375–377). Ethics reduced to group consent thus also effectively transforms “communities” into sites in which such consents may reasonably be procured, differences between and ambiguities within groups notwithstanding. HDGP project organizers’ first important efforts at “manag[ing] the open conflict about their work,” in other words, was to propose “a stable set of principles and technical guidelines for decision-making” drawn from the “apparatus of contemporary bioethics” (Brodwin 2005:156; see also Harry 1994; Juengst 1998b; Marks 2001; Reardon 2001).

The salves sought to address the HGDP controversy and the consequent disruptions of scientific endeavor were in the realms of the ethical, procedurally defined. “Communities” were where the controversies had begun, communities were a crucial means to scientific ends, and so communities were necessarily the sites where corrective ethical procedures had to be carried

out.<sup>26</sup> As such, although MEP addressed in some fashion the sample-collection methods deployed in the HDGP, the project's scientific rationale remained virtually intact. The problem of the HDGP (and other similar initiatives), as organizers seemed to conceptualize it, was primarily one of means and mechanisms, not so much of ends.

The same "rhetorical act" (Brodwin 2005:170) that labels "ethics" both problem and solution to the HGDP controversy thus also separates, or takes for granted the separation of, "ethics" from "science," making the former the means to the latter. The rush of HGDP critiques made no such clear distinction, for example turning Cavalli-Sforza's statement—that genetics "should be the last nail in the coffin for racism" (quoted in Schoofs 1997)—on its head by showing that genetics could function as a tool of racism and biocolonialism, armfuls of good intentions and progressive ideas notwithstanding. Well-meaning and self-described progressive scientists' abilities to speak for the greater good were hampered amidst the chorus of criticisms that broke down any obvious or universal claim to represent it. And yet, given the consequently overwhelming focus on ethics as something apart from science itself, the claim of genetics to do good, to be able to do good, remains protected at the very least as a possibility. Quite probably this broad claim should be self-evident, but the point bears stressing to indicate the different qualities of ethics and science in relation to one another: the moral moorings of ethics brought to bear on, but ultimately not to contain, the transcendent capacity of science. This is apparent in just the fact that there have been subsequent attempts at studying human genetic variation in the work of the SNP Consortium (see Textbox 3) and the International HapMap Project, each of which have grappled with the problem of "groups" in more and less elaborate ways. The SNP Consortium's reports, possibly bearing HGDP critiques in mind, mention only the use of DNA from donors of "diverse ethnicity"<sup>27</sup> or "donors with diverse geographic origins"<sup>28</sup> with the goal of creating a "high-density, high-quality" map in the "public domain, giving free and equal access to all in the worldwide medical research community."<sup>29</sup> The HapMap Project's greater reliance on population-based sampling, however, lands it in an extended embrace with ethics to (partially) address the

ongoing challenge to avoid misinterpretations or misuses of results from studies that use the HapMap. Researchers using the HapMap should present their findings in ways that avoid stigmatizing groups, conveying an impression of genetic determinism, or attaching incorrect levels of biological significance to largely social constructs such as race. [International HapMap Consortium 2003:793]

Such precautionary moves place ethics alongside other conditions such as genotyping cost, improved analytical methods, and specific kinds of future studies, which together will allow for HapMap's potential to be fully realized (2003:793). In this narrative, ethics represents the means of access to data that will then need to be genotyped, analyzed, and used in future studies: it is a series of definite steps en route to the production of scientific goods. HapMap organizers acknowledge potential risks to communities in the form of discrimination, stigmatization, among others "that may not be evident to outsiders" (2003:792). Because "much of the [HGDP] controversy arose as a result of misunderstandings brought about by insufficient community involvement," risks will be addressed and future misunderstandings averted by sufficiently undertaking "Community engagement, public consultation and individual consent" (International HapMap Consortium 2004:471; 2003:792).<sup>30</sup> All this should be undertaken so that, ultimately, under optimal scientific conditions, "all major world

<sup>26</sup>Eric Juengst is critical of anointing communities as gatekeepers in this fashion (see Juengst 1998b). Whether this is appropriate or not, I mean simply to point out that "communities" become the loci of ethical treatments, as a result of identifying them as sources of potential controversy and bodies capable in that of deterring science research.

<sup>27</sup>See [http://www.nature.com/nbt/journal/v18/n8/full/nbt0800\\_809a.html](http://www.nature.com/nbt/journal/v18/n8/full/nbt0800_809a.html).

<sup>28</sup>See [http://snp.cshl.org/news/snp\\_hgp\\_collab.shtml](http://snp.cshl.org/news/snp_hgp_collab.shtml).

<sup>29</sup>See [http://snp.cshl.org/news/consortium\\_pr.shtml](http://snp.cshl.org/news/consortium_pr.shtml).

populations can derive the greatest benefit” (2003:793). In this, HapMap organizers admit that researchers can no longer wield uncontested claims to serve the greater good, but the problem for them is still largely one of access, method, and design. With a worldwide benefit foreseeable, a reformulated standard of evidence and mode of persuasion (Brodwin 2005:170) in the shape of ethics protocols will surely mitigate the risks along the way.

**The SNP Consortium (TSC; <http://snp.cshl.org>)** TSC is a collaboration initiated in 1999 between pharmaceutical companies and philanthropic organizations to create a map of the SNPs distributed throughout the human genome. Although the project originally set out to identify 300,000 SNPs, 1.8 million were eventually discovered. In part to render this mass of data useable, the work of TSC has given way to population-based studies. For example, the Allele Frequency Project seeks to determine the frequency of certain SNPs in “three major world populations”: African American, Asian, and Caucasian. The International HapMap Project represents another population-based approach to the study of human genetic variation through SNPs.

I began this section on the temple lawn counting blood samples, now the problem of biomedical researchers, imagining their transport to Coriell in a packaging of Styrofoam and cardboard designed to protect them and prevent breakage en route. If I may restate the problem of the blood sample as not just one of packaging but also of how this blood is made good, in light of the above discussion the path to the good seems to cut through the domain of the ethical, defined in terms of research design. Personifications matter naught at this stage of encounter with bioethics, which values documentary procedures, records, and consents—what my colleague on the Houston-based ELSI Project, Jennifer Hamilton, dubs “ethical *provenance*” (2006)<sup>31</sup>—particularly as these are tied together under the rubric of “community consultation.”

## SIX: GOOD SCIENCE IN THE BIOETHICAL ENCOUNTER

The problem of the good in my account, however, goes beyond this specific terrain of the ethical as research design or sampling strategy. Although reformulations of the E in ELSI are critical to determining how (and therefore what) good can come of research on the human genome, these tend to overshadow other ethical decisions made in the research process that produce both good science and scientific goods: choices of technologies, analytical strategies, or the various ways in which researchers reflexively “care for the data” that has been gathered (Fortun and Fortun 2005:47). The problem of devising “ethical research design,” although obviously critical, is only half the story. The other half may be characterized by what Mike Fortun calls an “ethics of promising” that is so ubiquitous in genetics: neither “empty hype” nor “formal contract,” but something uncomfortably in between, crucial to “an emergent technoscience like genomics” (2005:158). Here, indeed, is the domain of the abstract from which lofty promises can be made to blood sample donors on temple grounds, foregrounding the possible good of genetics despite the risks, despite the documentary and other constraints of ethical research praxis. Here, in the indeterminate spaces beyond ELSI, the potential value

<sup>30</sup>See Sarah Franklin notes the stress on “better scientific information” reflects a “traditional assumption that the more the public understands about science ... the greater their approval of scientific innovation and technological change” (2001:340). In her account, this assumption has been roundly challenged both by social scientists and by studies commissioned to study public understandings of (in that case) cloning. Although HapMap shares the concern with “contain[ing] public mistrust of scientists” and maintaining “public goodwill” (2001:342), its substantially different goals (and its distance from issues like cloning) seem to allow it to stick fairly close to traditional assumptions that correlate public knowledge with support for technoscientific possibility—an assumption that is shared in this instance by the “public” in question, Indians in Houston.

<sup>31</sup>“Ethical *provenance*” is the idea that scientific objects come with particular provenance, which attests to their legitimacy as ethically procured samples (specifically through documentary processes of community consultation and informed consent; Hamilton 2006). Writing of Theravada Buddhists in Sri Lanka, Bob Simpson asks what sorts of schemes for “ethical publicity” (Cohen 1999:145) are produced by different cultural contexts (2004:842). I read ethical provenance as a specific characterization of ethical publicity, specifically applied to the material substances of biomedical research.

of genetic research becomes a transcendent, public good—at least in the sense of being nonrivalrous and nonexcludable, beyond specific commercial or community control, much as the HapMap samples are once they have been signed away. The transfer of substance from bodies to vials, then also marks the moment when blood enters a wholly different imaginary built on an ethics of promising, driven variously by need or commitment to produce scientific good(s).

The point bears stressing particularly for its consonance with Indian views: for a number of my Indian interlocutors, too, the promised “good” of science can and should transcend ethics. Whether there is trust between researchers and subjects, whether data is sabotaged or misutilized, one retired engineer with an avowed commitment to research shrugged his shoulders and accepted the certainty of “ethical issues,” likening the potential of scientific discovery to that of fire: “A fire can cook you a meal—a delicious meal, or it can also burn down a building. How we utilize the fire is what determines, you know, whether it’s beneficial or destructive.” I return to this idea below. For the moment, I want to draw the abstract once again into the ambit of the particular: what does it mean to speak of genetic research as a public good while still in the long shadow of the HGDP and so many as yet unresolved questions about the use of racialized categories in basic science research, the prospects of commercial genomics, the mechanisms for benefit returns, and more? Or: how might we account for the transcendent quality of science, its avowed disinterest in politics, the persistence of a necessary and necessarily abstract “ethics of promising,” within a more-or-less charged political atmosphere that tends to foster nothing short of an “ethics of suspicion” (Fortun 2005:161)?

Researchers who stand to become beneficiaries of the samples filtered through ELSI research are positioned at a critical juncture where more than one transformation occurs: individuals become human subjects, blood is turned into sample, ethnography (or its equivalent) gives way to bench science, ELSI yields to other technoscientific and ethical imaginaries—and the rhetoric of risk fades, albeit incompletely, into a rhetoric of promising. The HapMap engagement in Houston does not take me much beyond this point in the research process, so it is not possible to follow samples into these other terrains either as an ethnographer with a stated charge in this study or on behalf of donors who wish to know specifically what individual contributions may scientifically reveal.<sup>32</sup> That said, two things are discernible from this juncture. A backward glance reveals the complex politics and politically oriented constraints of sample collection outlined above, the details of the exchange of blood for research. Looking ahead, a distinction between (the value of) basic science research and (the realities of) policymaking comes into relief. Here is an abstract valuation, even an idealization, of “basic science” produced by the very politicized contexts of constraint—much as the value of philanthropy is given by the constraints of the market, in Parry’s assessment.

Allow me to explain, using the HDGP as but one example among others from which the desire for good science and a science that can do good, gains expression. The HGDP controversy and subsequent agitations over biopiracy and the prospecting of plant materials have focused overwhelmingly on the political orientations of science, sometimes going further to map out the links between the conduct of science and the commercialization of scientific products such as drugs (Duster 2003; Hayden 2003; Høyer 2005; Kahn 2004; Shiva 2000). By way of contrast, consider the comment of HGDP organizer and geneticist Marc Feldman, responding to the irony of “saving cells” when no such care has historically been taken to protect indigenous communities from physical and cultural decimation: “Look, if the Malaysian government is going to allow the Negrito population to be eliminated by selling their land to the Japanese

<sup>32</sup>Most often, donors want to know about their individual genetic makeup, specifically when they are concerned about identifiable ailments (diabetes, heart disease, cancer, etc.). We have often had to inform donors that no individual tests will be conducted on their samples, and to allow them to opt out of donating in light of this information, although they have almost never changed their minds.

timber companies, there's not much the Genome Diversity Project can do about that. *We're scientists, not politicians*" (Gutin 1994, emphasis added).<sup>33</sup> Henry Greely, author of the MEP, insisted further that there was "no commercial money in the project, no pharmaceutical-industry backing;" thus not embedded in the market, the HGDP represented a "pure science" initiative (Gutin 1994, emphasis added). At the time, Jonathan Marks matched Feldman's weariness with sarcasm in *Anthropology Newsletter*: "as if opening the veins of the indigenous peoples of the world might not constitute a significantly political act" (Marks 1995:72). Marks later remarks that the "purity of science was as illusory as the purity of the people the scientists wanted to study" (2001:373). In the face of so much cutting critique from indigenous communities and social scientists alike, it is near impossible to read the avowed commitment of the HGDP to "knowledge, not profit" (Gutin 1994) as anything but disingenuous, ill informed, or misguided. It is also perhaps difficult, by the same token, not to remain suspicious of such other endeavors to study human genetic variation so close to the lineage of the HGDP as the International HapMap Project.

Even so, rather than dismiss Feldman's statement and others like it as evidence of a lack of sufficient thought given to the political underpinnings of sample collection, I read such asserted separations of science and politics in a different light. Although genetic research controversies (like that of the HGDP) indicate on one level that science can never be pure, on another level they seem to generate the theory, at least among researchers associated with human genetic variation research, that science can and should somehow transcend politics and blatant commercial interest.<sup>34</sup>

This conception of science as a praxis that can be kept apart from politics and commercialism is nothing new. Jenny Reardon's account of scientists' discussions of race in the 1950s (and then leading up to the HGDP) shows that the pressing concern was not to reject the value of "race" as a research tool in the face of WWII violations, but to define it accurately, according to purely scientific criteria, and to ensure that that scientific definitions prevailed over the flawed social theories of the times (Reardon 2004a:49; see also Duster 2003:262–263). Bad science can happen, misuses are unfortunate and will abound, the conclusion seems to be. Coalescing personal, political, and economic interests can and does corrupt the outcomes of science research, as historical instances of commercialization or inattention to the rights and wishes of communities from Tuskegee and World War II to the HGDP and the case of deCODE Genetics in Iceland clearly show. Some conflicts may be contained by ethics, reigned in by Informed Consent limitations that delineate to what uses the HapMap samples may be put, or how findings based on HapMap should appropriately be presented (International HapMap Consortium 2003:793). But the HapMap Consortium take on ethics seem to indicate, much as Reardon's account of the 1950s discussions on the conduct of science research also shows, that science done properly, with accurate definitions in hand, with human data accessed via the conduits of ethics, ought to avoid foreseeable "misunderstandings" and so transcend social definitions—while not undermining social concerns as identified by communities, of course (International HapMap Consortium 2004:471). Looking at corporeal substances, asking what

<sup>33</sup>Along very similar lines, molecular geneticists and neurologists working on the biochemical or neurological aspects of violence in NIH-sponsored studies distinguish between their own work as "basic science" and the study of violence among groups as a "policy matter"—a distinction that then becomes justification for "assigning the bulk of science funding to 'basic processes,'" as Duster notes (2003:272).

<sup>34</sup>I cull this theory in part from statements made by HDGP researchers, of course, but equally from informal interactions with HapMap researchers and some geneticists allied with the Project. For some, the engagement with the social sciences is simply the cost of doing genetic research these days: ELSI programs are meant "to preempt the critics," as James Watson once said (Fortun 2005:162). Others are as practical, but far less cynical about the need for and value of ELSI contributions. Still others match the "resentment" that marks many science studies analyses with an equally oppositional critique that asks, for instance, when social scientists will stop blocking the possibilities of genetic research by their consistent indictments about the political nature of science. The reading I offer here is meant to take stock of such varied perspectives, to account for underlying commitments to the "promissory [nature of] sciences like genomics" and above all not to presume "the superior knowledge of the 'social' analyst" (Fortun 2005:161, 160).



sorts of goods and problems these represent, how they are requested, documented, and processed sheds some light on the processes by which this underlying pull gains expression.

## SEVEN: THE “COMMONS” OF THE BIOETHICAL ENCOUNTER

There are, then, two theories that I juxtapose to see them as variations on a theme: a theory of gifts that ought to be free (but are not), and a theory of science that ought to be pure (but is not). Underlying the one is an acknowledgment of the pull of the market; underlying the other is an acknowledgment of the pull of the political, on the one hand, and the commercial, on the other hand. Both recognize some version of what Derrida calls “*the impossible*” in his writing on gifts (1992:7), but both insist stubbornly on preserving, however fleetingly, the possibility of that which appears obviated by the rules of exchange. Both indicate a commitment to doing good works, even if “find[ing] out how to do this is less than straightforward” (Fortun and Fortun 2005:50). Both express the wish for a commons within which an abstract greater “good” can freely circulate, and with this the strikingly similar hope that the expenditures, perhaps also risks, of producing such “goods” will “eventually prove to have been well justified in terms of its benefits to *world health*” (International HapMap Consortium 2004:474, emphasis added).

The idea of what Catherine Waldby and Robert Mitchell (2006) call a “biomedical commons,” a subset of a wider intellectual or information commons, is itself nothing new. The consolidation of the commons idea is, historically speaking, a response of sorts to the territoriality of intellectual property legislation and the sense of increasing encroachment onto the open domains of the “public.”<sup>35</sup> Such encroachment is not spearheaded by private and corporate interests alone: the available literature on intellectual property suggests that all academic institutions now readily lay property claims to such “fundamental discover[ies] as gene-splicing” and, indeed, “proclaim an entitlement to control and profit from commercial use of their government-sponsored inventions without apology for resulting restrictions on subsequent research and development” (Rai and Eisenberg 2003:310). Further, it is not always certain that corporate interests will endorse the push to patent any more than grassroots organizations or patient advocacy groups will seek to oppose it. Private and public seem oddly allied, rather than opposed, in recognizing the pragmatic potential of intellectual property protections as well as the possibility that “intellectual property rights ... could create significant barriers to subsequent research and product development” (Rai and Eisenberg 2003:298–299). To say this otherwise, private–public collaborations share concerns over the formation of “patent thickets,” and routinely negotiate claims to intellectual property rights precisely by taking recourse to the “public domain” as an ethical site from which to bypass restrictive regulatory practices (see Waldby and Mitchell 2006:150–156; also Rabinow 1999; Rai and Eisenberg 2003).<sup>36</sup> The tension remains, however, and corporate promises of a “biomedical commons” seem more susceptible to skepticism than capable of garnering praise.

Nonetheless, I think it is important to note the existence of a number of “open sources” in biomedical research, not the least of which are data from the Human Genome Project (GenBank), HGDP data, and subsequent data produced by the SNP Consortium and the International HapMap Project.<sup>37</sup> With lesser or greater emphasis, in lesser or greater detail,

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<sup>35</sup>Note for instance the rationale offered for the establishment of Duke University’s “Center for the study for the public domain”: the Center’s founders and faculty co-directors ([James] Boyle, Professor David Lange, & Professor Jerome Reichman) see the focus on the public domain as a necessary part of the intellectual property system, not an attack on it.... “Over the last twenty years intellectual property rights have expanded dramatically, in length, and reach and scope and practical effect,” says Boyle. “Now intellectual property rights are asserted over gene sequences and ‘business methods,’ over technologically protected material on the Internet, over the images of dead celebrities, and even in some places, over straightforward compilations of facts. Little by little, the public domain has been shrinking. We hope that the creation of this Center within Duke Law School’s Intellectual Property Program will help to bring greater balance to the scholarly and public policy debate on these issues.” [http://www.law.duke.edu/news/current/20020905pdic.html]

each of these initiatives are openly committed to creating “a vigorous public domain [that] can supply a meeting place for people, information, and ideas that might not find each other in the course of more organized, licensed encounters. Information in the public domain is accessible to users who otherwise would be priced out of the market.”<sup>38</sup> Scientific databases created as “community resources”<sup>39</sup> and “as public works” reflect at least one way in which scientists in industry and elsewhere express their ethical obligations and “challenge entrenched ideas about how one goes about serving the public good” (Fortun and Fortun 2005:50). Such broad scientific commitment to the creation of a biomedical commons seems analogous at least in spirit, then, to the idea of the commons expressed by the Indian wish that research contribute to “the good of humanity.”

But how far does the analogy of spirit go? No doubt both scientists and members of the Indian community share a commitment to serve a larger good, but, as I have shown in the sections above, the means by which this “good” is served are as strikingly different as the hopes expressed are similar. As Christopher Kelty has written of copyright holders and “commoners,” “both of these groups articulate these ends by reference to the same concepts: freedom, democracy, progress, innovation, individual choice, but also increasingly, cultural autonomy, and ‘community’ ” (2004:557): a common vocabulary indicates an intersection of abstract ideals, but masks the divergence of local/moral objectives. Indeed, the common wish for “public access” or public benefit notwithstanding, the concept of the “greater good” articulated by Indians references a collective beneficiary qualitatively very different from the “public” mobilized in scientific discourse. A SNP Consortium call for genomewide SNP-based linkage studies makes the point quite clearly when it simultaneously emphasizes the Consortium’s “*minimal*” goal of “maximiz[ing] the number of SNPs that enter the ‘public domain’ ” “*without intellectual property restrictions,*” and that the “public domain” is a space defined by patent law (emphasis added).<sup>40</sup> Waldby and Mitchell usefully point out that intellectual property is, in this, configured to “create permeabilities” between public information and privately held knowledge: the boundaries in between that which is privately protected and that which is openly accessible are porous rather than hermetically sealed (2006:185).

Donors in the Indian community are, however, less familiar with such con- figuration of intellectual property to enable a commons, and far more familiarly outraged by the efforts of

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<sup>36</sup>Consider also the “defensive publishing” strategies of some companies, engineered as preemptive moves to prevent other companies from establishing virtual monopolies in the area of genome sequencing. The 1992 move by Smith-Kline and Human Genome Sequences to find and patent gene fragments called “Expressed Sequence Tags” (ESTs, that could have defined the scope of drug research and channeled royalties accordingly) was effectively preempted by Merck, which paid Washington University to discover ESTs and place these in the public domain sooner. The British-owned Wellcome Trust, one of the largest medical charities in the world, made a similar preemptive move to dramatically increase funding for genome sequencing research following Celera Genomics’ announcement of its intention to patent genes with commercial promise. In April 1999 (the next year), ten private companies joined Wellcome Trust to form the SNP Consortium, recruiting academic institutions (such as the Whitehead Institute for Biomedical Research, Washington University School of Medicine, and Cold Spring Harbor Laboratories) to identify SNPs in a directed “effort to ensure public availability of SNPs that are generated,” “giving free and equal access to all in the worldwide medical research community” ([http://snp.cshl.org/news/consortium\\_pr.shtml](http://snp.cshl.org/news/consortium_pr.shtml)). Such forays into the “public domain” are no doubt strategies engineered to protect commercial and corporate interests—but not only commercial and corporate interests are protected, as a result. As such, they represent contemporary reformulations of corporate philanthropy: “*universalistic* conception[s] of purely disinterested exchange” that develops as the logical flip side of the practices of market exchange (Parry 1986:486).

<sup>37</sup>There are also such other public access databases as The GDB Human Genome Database and The Single Nucleotide Polymorphism database (dbSNP), and online forums like MedCommons committed to facilitating communication between patients, physicians, hospitals, public health agencies and research labs “achieving interoperability ... without coercive credit-bureau-like information warehouses” (<http://www.medcommons.net/#>). “Open source” initiatives proliferate in the world of programming and software development, of course. Examples include the Bioinformatics Organization, the Open Bioinformatics Foundation, and the Creative Commons, among others.

<sup>38</sup>See [http://www.ornl.gov/sci/techresources/Human\\_Genome/elsi/patents.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/elsi/patents.shtml).

<sup>39</sup>As in this NHGRI site with guidelines for prepublication data release: <http://www.genome.gov/10506537>.

<sup>40</sup>See [http://snp.cshl.org/news/RFA\\_1200.shtml](http://snp.cshl.org/news/RFA_1200.shtml) and <http://snp.cshl.org/about>. Quite possibly the emphasis of the SNP Consortium on creating a “public domain” resource is a response to heavy industry patent-seeking on large numbers of SNPs, “provoking concern on the part of both NIH and the pharmaceutical industry about the potential for balkanization of intellectual property rights in this important resource” (Rai and Eisenberg 2003:298).

such U.S. companies as W. R. Grace and Company and RiceTech to patent the antifungal properties of neem and strains of basmati, respectively. In a widely publicized, lengthy, and expensive legal battle, the Indian government fought and won its case to revoke a U.S. patent on the therapeutic properties of turmeric, granted to (Indian American) researchers at the University of Mississippi Medical Center. Then in 2001, the “Neem Campaign” led by a consortium of NGOs working in India and abroad succeeded in revoking a patent issued by the European Patent and Trademark Office after a four-year struggle. Indian news agencies and activist organizations continue to report on the number of other patents on indigenous plant ingredients that remain still to be tackled (Dasgupta 1999).<sup>41</sup> In combination, such cases have spurred some significant preemptive moves: an Indian government collaboration headed by the Council of Scientific and Industrial Research (CSIR) launched an online database known as the Traditional Knowledge Digital Library (TKDL) precisely to establish Ayurvedic medicine as a “prior art” in the face of patent claims; the Indian Council of Agricultural Research (ICAR) has begun DNA fingerprinting of crop varieties in its gene banks in anticipation of future patent disputes; and NGOs like Navdanya bank seeds to ensure “seed sovereignty” in the face of the “many distortions” of U.S. patent law that runs counter to a “fair and honest global Intellectual Property Rights system” (*Nature Biotechnology* 1999; Shiva 1997b).<sup>42</sup>

In conversation, Indians are quick to point out that plants like turmeric and neem have been in common use in India for hundreds of years, their medicinal properties well-known. In more than a few casual interactions, interlocutors mentioned with pride that research labs (incl. one at the prestigious M. D. Anderson Cancer Center in Houston) have begun to demonstrate the anticarcinogenic and other curative properties of turmeric. The value of such research, however, is clearly in its confirmation of ancient Knowledge and of those common practices arbitrarily deemed unscientific by prevailing medical ideologies; the value of research on turmeric or neem is not its ability to create claims to exclusive ownership.<sup>43</sup> For Indian donors, then, the abstract notion of the “good” properly transcends interests defined exclusively by patents; the logic of patenting is not a “limited monopoly” but is itself a major deterrent to the development of public goods for the common good. To this extent, Indians are actually allied more with the consortiums battling the encroachments onto what Vandana Shiva calls a “*traditional* intellectual commons” with all its “diverse traditions of creativity,” than with consortiums promising access to technical information via the public domain in furtherance of specialized genetic research (Shiva 1997a:10, 8).

Public-private collaborations in genomic research such as the SNP Consortium and the International HapMap project, however, seem to face the realities of patent law and the pressures of commercialization in much the same way they face “ethics”: as a set of constraints within which to operate, even at times to take advantage of. The commons of blood—human populations—are paradoxically inaccessible for research until they are extracted by “ethics” and inserted into other, more enabling, frameworks. Only at the moment of donation does the “citizen-donor” become an “open source of free ‘raw material,’ ” and that through the rhetorics of giving and serving (Waldby and Mitchell 2006:184). Blood turned into sample then becomes

<sup>41</sup>The Indian NGO Navdanya, a seed collection and biodiversity conservation program of the Research Foundation for Science, Technology and Ecology (RFSTE), lists patents on at least 12 other plants and fruits used widely in India that need to be revoked still (<http://www.navdanya.org/articles/turmeric.htm>). RFSTE was part of the coalition that battled the European Patent and Trademark Office over the patent granted to W. R. Grace for the properties of neem, and is led by the writer and activist Vandana Shiva.

<sup>42</sup>See TKDL: <http://203.200.90.6/tkdl/LangDefault/common/Home.asp?GL=Eng>; Navdanya: <http://www.navdanya.org/about/index.htm>.

<sup>43</sup>And, yet, as Sita Reddy points out, the Indian discourse on heritage and ownership is paradoxical, at best. Such defensive publishing as the Government of India undertakes is to be distinguished from that of the SNP Consortium for it often “ends up *removing* [Traditional Medical Knowledge or TMK] from the public domain in an attempt to return it to its alleged [*cultural*] creators”—while simultaneously protecting it from patent and other claims to commercial ownership (2006:162). This effort to return information to a traditional commons in practice, then, creates new forms of cultural, national, and state ownership.

immortalized cell line, which in turn becomes the source of material substance to be distributed to interested research labs as individual lines or panels. The alienation of blood into samples that takes place on the temple lawn is still well within the purview of IRB-regulated “ethics” and Human Subjects protections; the alienation of blood occurs ironically as a result of its passing through such regulatory filters as IRBs use to define the ethical treatment of Human Subjects.

The association of blood with its human donors loosens precisely at the moment when it is claimed by procedural ethics, in other words. Samples obtained from Coriell’s NIGMS Human Genetic Cell Repository then bear no connection or even resemblance to the substances shipped from Houston. Their alienation from Human Subjects is complete in the sense that working with the samples no longer will “involve an intervention or interaction with the individual [for] the samples do not contain identifiable private information.”<sup>44</sup> Extricated thus from the face-to-face contexts recognizable of human interaction, blood is rendered accessible, “legible,” “communicable,” “medium-independent,” a repository of information in its own right, and a “speculative asset” such that the generation of intellectual property now becomes concretely possible, even desirable (Gere and Parry 2006:46–47; Waldby and Mitchell 2006:184).<sup>45</sup> The Coriell Repository naturally, then, requests citations and reprints of publications that utilize Repository samples, only asking researchers “not to name the population from whom the samples were obtained, if this information is not essential.”<sup>46</sup> What belonged once in the “commons,” was inaccessible for its existence in the commons, by its absorption of ethical *provenance* (Hamilton 2006) and consequent physical transformation now enters spaces chopped up by IPRs and all their attendant legal regulations and protections, even as the remaining threads of “human subject” identification continue to be loosened. “Goods” are produced by cutting through such dense institutionally modulated, legally produced, market-mediated thickets, not so much by challenging the terms of U.S. patent law directly as the Indian Government and an array of NGOs have done with patents issued on neem and turmeric.

## EIGHT: COSMOLOGIES IN THE BIOETHICAL ENCOUNTER

For donors and for researchers, the constraints of production thus take on different form and therefore represent different paths to some still abstractly common notion of “greater good.” Their expectations—of one another, of the community engagement process, of the research that samples enable, and of the nexus of interests that sustain this entire endeavor—are linked at points, but quite asymmetrically so. At base is a transaction, something given to maintain the possibility of technoscientific progress in medicine. But what exactly is transacted for the sake of this wish? Members of the “engaged community” give time, donors give blood, a few hours or a few tablespoons as price to pay for the service of local temple, then “community,” and beyond it humanity: concentric commitments that mark the continuum between the abstracted local and the abstracted ethical. Donors expect researchers to adopt the same commitments: give time, channel resources, expertise, and contacts for the sake of local organization, and the “community” whose well-being matters to the overall health of the body politic. How much researchers involved in the project of community engagement and setting up the interface between “genetics” and “society” (in this instance anthropologists and bioethicists) decide to accede to such expectations is subject to some negotiation, of course. Far less negotiable are the exchanges that researchers working with “human subjects” must

<sup>44</sup>See <http://ccr.coriell.org/nigms/comm/order/instructions.html>.

<sup>45</sup>See also Waldby on the creation of biovalue, which she defines thus: “the yield of vitality produced by the biotechnical reformulation of living processes to induce them to increase or change their productivity along specified lines, intensify their self-reproducing and self-maintaining capacities” (2002:310).

<sup>46</sup>The request is made on Coriell’s “Assurance Form” outlining the terms and conditions for use of cell lines obtained from the NIGMS Repository: one of a few documents governing those future transactions, so to speak. See <http://ccr.coriell.org/nigms/comm/order/assurance.pdf>.

make to facilitate biomedical research and make its wide promises seem real. “Ethics” as procedure and as performance is the price paid here to grease the nonmonetary aspects of the transaction. “Ethics” justifies the taking of blood by imbuing it with ethical *provenance*, and opens the possibilities of research and of all the monetary and nonmonetary benefits that could then accrue.

Certainly, Indians to whom we spoke identified with this process to varying degrees, tolerating consent documents (either as necessary evils or as “legal mumbo-jumbo”) but also appreciating being asked to give form and substance to a study that recognizes their citizenship, or confers it through participation in a project of surely Gujarati, surely Indian, quite possibly South Asian, and then potentially global significance.<sup>47</sup> Not just a route to citizenship in this shifting sense, but the HapMap project also helps create an opportunity for service, a value in its own right.

Further, as it happens, Indians in Houston have been quite happy to endorse the value of “research”: “research” in the abstract as yet another shorthand reckoning of the “good.” Indians in Houston have not sought to demand that scientific progress be unidirectionally toward this good either. They are realistic about risks and misuses, placing responsibility for monitoring and reporting with the brokers of the transaction—me, my colleagues, the Baylor College of Medicine behind the study: meeting interlocutors at community events, “how is your research going?” is the question I am always asked, when I generally think of this work as being centrally about them. Indians do not usually presume that any new uses of race (or caste) classifications, those specters of stigma and science research gone awry, are necessarily deterrents to scientific progress. Alluding to a quintessential Indian expression of the “good” in the figure of Lord Rama, “and how many heads did Ravana have?” asked one interlocutor, casting the ratio of possibilities of good to misuse as 1 to 10, but placing faith against the odds, as it were, in the sureties consolidated in the figure of Lord Rama himself. “The good has such an overpowering influence, it is not so much the quantity of the good; it is the quality,” he concluded. In fact, on this level Indian expectations of researchers on this level are minimal. This is largely because genetic research is not a specific community priority—important, yes; welcomed, yes, for all the various reasons touched on above; but a priority at any level closer than the generalized abstract, not particularly. For donors and for researchers, then, the transaction is easy enough to cement because the expectations one way are minimal to abstract, and the other way are facilitated by going through the institutionalized, relatively clear motions of procedural ethics.

So this story of a sample-collection initiative in a metropolis called Houston ought to be a simple one, and, on some level, it really is. Observers of science in motion, who may have looked to this undertaking as the site of the next potential controversy, including those of us involved in the community consultation, are likely to be disappointed, it seems. Our own wariness of controversy as researchers responsible for this study, given our knowledge and prior professional engagement with HGDP and related critiques, cannot be understated. “Why are you telling us all about what you have *not* found in Houston?” a researcher working with another HapMap community consultation project asked, following a workshop presentation I made on behalf of our research group. The answer, of course, is because such projects as ours were effectively set up to test for controversies: to gingerly approach doorknobs, to ascertain their temperature so as to decide whether or not or how to enter rooms in which fires are already

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<sup>47</sup>It is noteworthy that the citizenship conferred is not of the United States, within whose borders this research is taking place, and from whose government (via the NIH–NHGRI) the funding for the Houston largely research originates. The questions and methods of such studies are given by specific U.S. histories of research abuses and specifically U.S. responses to homegrown controversies, as I have tried to indicate. But this more-or-less visible frame seems nonetheless to generate identifications that either bypass or transcend the United States, much as Indians themselves do in their travels, lives, business dealings, medical and financial decisions and more, shuttling in between local communities here and there, and the abstract world in which all activity is suspended and to which all intangible benefits accrue. Space considerations limit me from considering the issue of bio/genetic citizenship in detail; for more on this theme, see Bruce Jennings 2004, Rayna Rapp et al. 2004, and Nikolas Rose and Carlos Novas 2004.

burning. Controversy establishes the value of bioethical exploration, as cases like that of HDGP indicate. “Ethics” in the shape of community engagement is then a precaution, a water hose to douse flames, or a risk assessment study; we are firefighters all and the negative test result, then, is in reality a positive one. What we did not find is in many ways more important than what we did, and what we did find—a healthy regard for Knowledge—was, as our research assistant Corrie Manigold remarked, quite anticlimactic. My colleague Jennifer Hamilton pointed out further that the absence of controversy may be precisely a consequence of community engagement: the asking averts the argument, so to speak. So, once again, if it is the case that our wariness was effective, there ought to be reason to celebrate.

Celebrating the absence of controversy would, however, miss accounting for the details of the transaction that I outlined in the course of this article. Obviously, there is an overlap between Indians’ and geneticists’ commitments to technoscientific progress—but only a tenuous overlap, not a complete collapsing of common goals. If the “goods” (in both senses) are different and differently produced, if the paths to the production of these “goods” are distinct, if the notion of the “public” is only barely coeval with the notion of the “commons,” then there are in fact quite separate cosmologies sustained by those doing the giving and those doing the taking of blood.<sup>48</sup> Having said above that the Indian community’s expectations of genetic research are minimal, it may appear strange now to make the opposite claim, that Indians are asking for something much larger than the army of researchers assembled to understand their priorities could ever hope to deliver.

Let me explain. Although it is true that Indians do not demand that certain specific goods and services be produced as a result of their sample donations, or even that science comport itself in accordance with the spirit of their gift, they do request the effective equivalent of *dāna*. In other words, the condition of the transaction is that the good gift of blood be passed along in the form in which it was received. Biogenetic substance should remain something akin to *dāna*, the gift that apparently obviates the distinction between interest and disinterest in exchange, that is wholly alienated in the act of giving. Researchers may benefit from their work via the samples collected, but their works in turn must reproduce the disinterested largesse of *dāna*, or at least the compassion of *seva* (service) to the greater good. This is not an enforced condition, to be sure, but is tacitly built into the exchange between “community” and “geneticists” nonetheless—is even implicit in the community’s simultaneous support of our research and their claiming of me as someone positioned to do these and other good works.<sup>49</sup> But is it really possible for blood to retain the qualities of *dāna*? Samples freely given were meant then to circulate freely, but, realistically, can they? Can the asymmetric expectations of “Indian community” and “researchers” be satisfactorily aligned through community review?

Purified first by the association with Indira Gandhi or the Saints of the Swaminarayan Temple or the idea of “research,” blood is ethically and then legally purified to the point of unrecognizability. Blood becomes meaningful then not so much because of the spirit in which it was given (what access or need do geneticists further down on the transactional chain really have to the ethnographic materials we have amassed?) but as a material resource, a channel to spaces both regulated and opened up by intellectual property rights and beyond it the neoliberal market-place. *Blood Must Circulate*, says the Jeevan Blood Bank, the committed insistence of

<sup>48</sup>My thanks to Chris Kely for prompting me to articulate the issues along these lines.

<sup>49</sup>And I have been claimed as such, for example to help organize health fairs and lectures on Gandhian thought through my professional associations, publicize seminars on Kannada culture organized by the local Kannadiga association (Kannada Vrinda) in collaboration with the Museum of Fine Arts Houston, and also to help create and teach courses and mobilize support for an India Studies Program at the University of Houston. When viewed from a strictly professional standpoint, these undertakings are clearly outside of the parameters of the ELSI-HapMap study. For Indian interlocutors, however, such undertakings are my service responsibility to my community, natural extensions of my professional positioning. This expectation of further good works was not inescapable, of course, but it was a palpable pressure in my experience; praise flowed freely when I participated as the community wished I would.

its motto bespeaking the very difficulties involved in ensuring its free circulation beyond and between individual bodies, around the market rather than through it. And blood given to genetic research does circulate, I think it is fair to say, but not nearly in as unfettered a fashion as donors would like. In the donor imaginary, blood moves from the veins of the local/moral into the spaces of the ethical/abstract, the unknown, largely unfamiliar, and almost wholly speculative spaces of scientific discovery. Less visible from that perspective are the conceptual, procedural, and legal redirections of “blood” flow into other circulatory systems that channel and filter and pump it in all manner of predictable yet unforeseeable ways, through repositories and research labs, into the speculative economies of intellectual property rights (Cooper 2006; Strathern 1999). Moving from open source online databases and nonprofit repositories like Coriell into labs, research publications, and clinical practice, blood inevitably loses the character of *dāna* and becomes inalienable once again—this time from the research and writings of authors (myself and this article included), practitioners in clinics, and other recipients of the donated samples or the innovations they help generate. Blood as ethically procured material resource exists within, is meaningful only within, this entirely different cosmology.

Presenting this scenario to donors inevitably provokes the last-ditch “still, somebody will eventually benefit”: a rationalization that absolves one of individual responsibility to ensure that benefits will properly accrue, a gesture of alienation that admits that individual control ends with the contribution of a vial, or simply a firmness in the face of my posed cynicism. The less-than-perfect realities of market–model exchange may well be less important than the expression of desire for idealized gifts and idealized benefits: as Parry suggests, the ideology of the pure gift and the ideology of self-interested exchange are mutually implicated. To the (limited) extent that the HapMap project organizers speak also of the ultimate beneficiary of genetic research being “world health” or “world populations,” they, too, speak an idealized language of abstraction very similar to that of donors. The moral world of community consultation is translated, now into abstractions of global proportions. We do not know the channels yet, or the cascades or the signaling pathways (borrowing metaphors from molecular biology), but no doubt at the end is a target, a somebody who will benefit. The familiar stranger makes cameo appearance yet again, this time to give reality to the promise that moves the ethical mountain, but then still disappears.

## NINE: GOODS AND/AS SERVICES IN THE BIOETHICAL ENCOUNTER

“*Dāna*” is offered as the literal translation of “donation,” understood as not sale, but gift. When this concept is deployed in ethical discourse to evaluate the question of participation in genetic research, my interlocutors in Houston introduce images of King Shibi cutting piece after piece of his flesh to match the weight of a dove that came to him seeking protection from its predator, a hawk—a bodily exchange of a most literal kind; of Karna born with armor and earrings given to him by the Sun, his father, giving away this “skin” for it is his Kshatriya obligation to give to Brahmins who ask; of the sage Dadhichi, whose bones alone can fashion weapons to defeat the demon (*asura*) Vrutra. In such instances “the gift embodies the person” as Parry notes (again echoing Mauss), and the giver recognizes his recipient—even this stranger is recognizable as a type, a Brahmin—but then gives with the knowledge that the gift must be wholly alienated, the donor’s proprietary rights wholly eliminated (Parry 1986:461).<sup>50</sup>

<sup>50</sup>It is not possible to use a very strict definition of *dāna* in this discussion because perhaps more than one form of giving is collapsed, incommonusage, into the concept of *dāna*. *Dāna* in classical theory is strictly a brahminical formulation: only Brahmins sought to and indeed could purify themselves by giving away inauspiciousness to appropriately unwilling others. In its contemporary usage, however, the concept is not restricted to Brahmins at all. Nor, by the same token, is the concept of *seva* (service) any longer restricted to lower-caste communities. There is a longer history to this than I can track here, going back to pre-Independence social reform movements that reconfigured not only caste, but equally the place of donation and the responsibility of service in Indian life, separating these from *jāti* obligations. In any event, the contemporary usages are not group specific but far more general, to the point of being decontextualized and abstract, needing once again to be placed in contexts and made moral. My argument here is focused in part on how the conversations about giving blood make this latter move happen.

Alongside such rhetoric, however, is another language and rationale about service. The gift of blood for transfusion is gift, social responsibility, community service, and even nationalist service in concentric circles. The gift of blood for genetic research in my experience is similarly configured as contribution to the greater good. Recipients are unknown, but recognizable nonetheless as abstract types, whether “people in need of a life” or “genetic researchers.” And yet, because these are abstract and idealized types, because the cause being supported is an “ethical” one, a variety of personifications are deployed: saints, nationalist heroes, politicians, geneticists, even anthropologists seen as brokers with moral (in the sense Kleinman uses the term) responsibility. But then how does the alienation of the gift occur? Especially in the HapMap context, in which, despite the necessarily loud promises of confidentiality (and implicit alienation), there are still ways in which donors are paradoxically encouraged to identify with their blood samples, treat them as their own and follow their postcorporeal existences as it were?<sup>51</sup> In this space where the ethical and the moral meet, are negotiated, and mutually constituted, the rhetoric of service becomes a contemporary corollary of the idea of *dāna*, in which the alienation of the gift from the donor is accomplished by offering it as service “for humanity.” The gift rendered as compassionate service (*seva*), ethical abstraction, is thus to be performed as though one is not the doer, thereby simultaneously collapsing the alienation of donor from gift, doer from the thing that is being done.<sup>52</sup>

Changing stances and looking at blood exchange from the point of view of the recipient-researchers, the picture shifts somewhat. Not only does blood become an ethical problem, needing therefore an elaborate apparatus that processes and dons it with the appropriate *provenance*, but it also seems that blood leaves the realms of the good and enters the realms of goods, thus acquiring new forms of inalienability.

The tension between the gift and the commodity has, of course, been widely discussed in the scholarly literature on blood, tissue, and organ donation. Richard Titmuss (1970) and much later Thomas Shannon (2001) effectively reproduce the distinction by making pleas for the elaboration of rhetorics of gifting to counteract commercialism. Other authors such as J. Laidlaw (2000) and Bob Simpson (2004) document but also question the seeming inevitability of an “inexorable drift” from gift to commerce using Jain and Theravada Buddhist ideologies of giving as counter examples (Simpson 2004:841). Simpson, in particular, identifies the Maussian gift as the source of tension, characterized as it is “by motivations which are intended to cut across the instrumental logics of exchange ... conceived and transacted precisely in order to violate the structural certainties of the economic realm” (2004:842). Derrida’s alternative, the gift as the impossibility, “know[able] only through the economic and political displacements that render it visible,” unearths the paradox of gifting long acknowledged in world religious traditions, which broadly concur that “the conscious and calculating self has no place in the act of giving” (Simpson 2004:842). Transactions with such religious underpinnings then become the means by which to rethink the “free gift” as remaining fundamentally alienable, capable of circumventing the market.

As I have tried to show in the course of this article, Indians in Houston would also like their gifts to be “free”: uncalculating donations that variously circumvent, challenge, or supersede the market. Insofar as this is a wish articulated in the marketplace, however, a desire produced by the strictures that markets place on the free circulation of ideas and objects, the extent to which it can be actualized is limited. Blood will circulate, to be sure, but not in the idealized commons. Instead, it will be transacted in the legally modulated public domain, alienated from

<sup>51</sup>This was a suggestion made at the second (of two) NIH–NHGRI sponsored workshops on community engagement in which I participated: one way in which to continue community engagement after sample collection would be to invite donors to the Coriell Institute in Camden, New Jersey, so that they could see where “their” blood samples were housed, and learn more of what was being done with them. It was offered particularly as a “gift” (if I may) to African communities who may not have such opportunities for travel.

<sup>52</sup>For more on the ways in which blood donation reconfigures *dāna* and *seva*, see Copeman 2007.



donors and Human Subjects alike, incompletely and unevenly alienable from those of its handlers whose work will extract its benefits for “world health.” The gift of blood for genetic research, then, calls to mind Appadurai’s definition of the commodity as “not one kind of thing rather than another, but *one phase in the life of some things*” (1986:25, emphasis added). Mary Douglas’s reading of the Maussian gift is equally relevant: the “gift complements market in so far as it operates where the latter is absent” (1990:xiv—although I would add [à la Parry] that the complement is also something of a critique of market modalities). When the gift of blood is made good and offered as a kind of service, its alienation from bodies and religious worldviews alike is complete. It becomes a useable, fungible good to be transacted still in service of such lofty scientific ends as “world health,” but inalienable now from the intellectual and commercial activity that infuses it with new social meaning. The moment of donation that links Indians with genetic researchers, therefore, is equally the moment when the (dis)joint between worldviews and the “mixed economy” of gift exchange becomes most apparent (Waldby and Mitchell 2006:9).

## TEN: FRAMES AND FRICTIONS IN THE BIOETHICAL ENCOUNTER

One relatively straightforward, central exchange has oriented both our research in Houston and this article: blood requested and given for the purposes of genetic research. This exchange summons Indians and researchers alike into an engagement with bioethics and, in that, brings multiple frames to bear on the exchange at hand. Some were larger or more obvious, and I have allowed them to lead me to the other, less visible frameworks in play through the sections of this article, following the central transaction of blood for research as it progressed.

We expected controversy of the kind that gives ELSI projects their rationale; controversy would ironically have given this encounter with bioethics a far more predictable form, and would have made cultural narratives more recognizable as narratives of oppositional difference. But controversy was not to be found in this study with Indians. On the face of it, then, there were no new lessons to learn from the Indian encounter with bioethics—or even any information of particular interest, aside from cursory overviews of “Indian and Hindu views,” to report via publications to medical professionals and genetic researchers. As I suggest in the course of this article, however, it is not only the perpetual threat of controversy that precipitates bioethics. Bioethics also takes form equally in other narratives about gifts and how they should be given, science research and what it should achieve, goods and how these should circulate. It bears stressing that the abstract and idealized overtones of these narratives are not indications of the naïveté of either a community of Indians or of researchers. Quite the contrary, such idealizations point to subtle reckonings of the very real constraints within which gifts are given, science is done, goods circulate—in short, the constraints within which bioethics routinely happens.

But what, in the end, are geneticists meant to do with the stories of Dadhichi or Karna or Shibi Maharaj, giving away their bodies to strangers who come asking? Of what interest is that material, also generated by community consultation, to readers of *Nature Reviews Genetics*, for instance? What is the “value added” beyond that of an additional chapter on “culture” contributed to the annals of bioethics? To borrow again from Kelty, the first-order “articulation” of culture has value only in as much as it is amenable to “operationalization” (2004). Such frames as this research draws on are ultimately incommensurable; their juxtaposition is an unwieldy undertaking, at best. Nonetheless, it is crucial precisely because it throws into relief the mixed nature of the economy at hand: of culture articulated and culture operationalized; of consonance and controversy; of gifts, substances, information, and commodities, produced by the linking of disparate worldviews in a single transactional chain. This is not a “simple mixed economy” in which gift and commodity status alternate, as Waldby and Mitchell note but, rather, presumes the “modification of both forms of value” (2006:184). Gifts, in my experience working with

Indians in Houston, do not stay gifts for long and *dāna* cannot retain its ideal form. They are each transformed into new goods through successive stages of the bioethical encounter, precisely (and ironically) to retain their good status: meaningful but ephemeral service, the legible stuff of research, and information on public internet databases. Commodities, too, are not uniformly stable, but themselves move in and out of gift economies and the collective commerce of the public domain. The deployment of “service” as an ideal practice for both “community” and “research”—one serves one’s community in much the same way research should serve community needs—in particular acknowledges the dominance, indeed the inevitability of interested, invested market–model exchanges. So also does the science community’s propagation of a public domain, undergirded as it is by claims to intellectual property rights, speak to the dominance of interested, legally overseen exchanges.

And, yet, underneath the flux, are theories of the good that bring misaligned narratives and misfitted frames into (partial and temporary) alignment such that goods can be transacted and circulated in the interest of the common good: they are the grease that allow incommensurable frames to interact with minimal friction. Looking at the interstices between the frames, at the points where they ought to grate and grind (but do not) makes it possible to gauge a critical response to the universals of market and legal rationalities—a response that bypasses the inevitable and intractable frictions of “worldly encounter” (Tsing 2005:1, 4). “Research produces Knowledge that serves the greater Good”: there is a “*universalistic* conception of purely disinterested exchange” (Parry 1986:486) at stake in conversations about genetics, an identification with something beyond the market that is generated precisely by the constraining logics of market exchange. Where the constraints are many and the threat of controversy constant, theories of universal good offer recourse to other imaginaries. It would have been easy enough to dismiss such “universal aspirations” as common clichés but for the “specific situations” of ethnographic engagement that make clear how abstractions are used in common interactions (Tsing 2005:2, 9). Ethnographic engagements between misaligned frames reveal how good gifts to be freely given sit alongside goods to be purposefully exchanged in the market: the (im)possibilities of each are rendered visible only by the contexts of their displacement. And insofar as there remains an important, sometimes influential, commitment to a commons beneath—the idea of open access or the idea of the free gift, however pragmatically or idealistically reckoned—then these are the tropes that grease daily exchanges made within marketplaces, bypasses to an ethical life within a world defined by somewhat less than ethical limits.

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