Genetic Research & Communal Narratives

by Dena S. Davis

The risks and benefits of genetic research extend beyond individual subjects. Genetic research can also affect the communities to which the subjects belong, by rewriting the narratives and reconfiguring the identities that members of the community share and live by. These far-ranging effects raise special concerns for obtaining informed consent, for which there is no simple solution.

Scholars and laypeople alike are fascinated by the study of people's origins.[1] Are today's *Cohanim*—Jews who identify themselves as descendants of the hereditary priesthood of Biblical times—really the genetic descendants of those early priests? Did all "indigenous" North Americans journey across the Bering Straits, and if so, when? Just as individuals "seeking their roots" have made family genealogy into a national craze, scholars have turned their attention to the family histories of ethnic and linguistic groups. Tudor Parfitt points out that the groups most likely to search for and invoke genetic evidence of their beginnings are those whose origins are somewhat ambiguous, and that societies whose ethnic borders are least crisp are the most likely to be fascinated with the search for "who they are." He claims, "The whole late twentieth century obsession with 'roots' was fomented in the all-too-reducible American melting pot."[2] One difference, however, is that Aunt Mabel is usually interested in researching only her own family tree, while scholars often train their spotlights on groups of which they are not members.

Genetic research, and the increasing prominence of genetics in medicine and science, poses special problems for the ethics of research with human subjects. Genetics is basically about inheritance in families and larger groupings of people. Most commonly it is ethnic groups that are the object of research. However, groups defined by geography or political history can also have communal stakes in how genetic research is conceived, carried out, and described to the public.[3] All this makes the implica-

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tions of genetic research for communities or groups ever more important.[4]

Traditionally, informed consent to research has been an individualized process carried out by a researcher and a single subject. If a protocol requires a thousand recruits, consent is still seen as a thousand individual interactions. Some scholars have argued that genetic research is different, however, because the risks and benefits go well beyond the individuals who actually agree to take part, and devolve instead upon the group as a whole.[5] Some commentators claim that group consultation, or even group consent, is a requirement of ethically acceptable population-based genetic research conducted on identifiable groups.[6]

One potential harm or benefit of genetic research is that it can either undermine or corroborate the group's creation story or communal narrative. The group or groups whose interests are at stake probably do not speak with one voice, however, and different subgroups may be differently placed with respect to the narrative; a creation story that is a source of power for one subgroup may serve to marginalize another subgroup. Given the mélange of communities—and groups within the communities—a "community" decision whether or not to consent to the research is not always an effective approach to guarding the rights of research subjects.

What Genetics Research Can Show

Genetic researchers often focus on groups because certain genetic traits can be concentrated in groups of people who descended from a small number of common ancestors, especially if those people were also geographically or socially isolated, and if they favored marriage within the group. Even when a group has no higher incidence of a particular trait than the general population, it is easier to see genetic patterns that are associated with that trait if other genetic factors are more homogenous. If you are trying to figure out if there are any outward physical markers for schizophrenia, for example, possible patterns of congruence will stand out more sharply in a genetically homogenous group than in a highly diverse one. This is why scientists seek access to relatively homogenous populations such as Ashkenazi Jews, Zuni Indians, or natives of Iceland.[7]

Another reason is to measure the comparative frequency of known alleles (alternative forms of genes) among different distinct groups—what one might call a comparative epidemiology of genetic variation. In 2002 the National Human Genome Research Institute announced the "HapMap" project, an international endeavor that looks at genetic haplotypes (big chunks of DNA that tend to get inherited as a block) for the genetic variants that link to major diseases. The project will begin by looking at Americans with ancestry from Northern and Western Europe, a group of Yoruba in Nigeria, and people from Japan and China.[8] The HapMap project seeks to fulfill the greatest hope of human genetics: that new advances in knowledge will lead to prevention and treatment of common diseases. A critical part of understanding complex disease causation is discovering the frequency of specific genetic variants across populations.[9]

The ethical concern shown by the HapMap researchers, and their sensitivity to the challenges of working respectfully with people from many different cultures, is impressive. Nonetheless, serious issues remain. The samples, once collected, will remain stored in perpetuity, available to researchers (with the approval of institutional review boards) for uses beyond their original purposes. For example, they could be used to study migration patterns, as Ellen Wright Clayton, co-chair of the project's ethics board, has acknowledged.[10] Geneticists Mary-Claire King and Arno Motulsky have written that "the DNA of modern humans contains a record of the travels and encounters of our ancestors":

> The genotypes of people living today are the result of ancient human migrations, the continuous appearance of new mutations, selection by climate and infection for genetic alleles that conferred a survival advantage, and mating patterns determined by cultural norms. By sampling genotypes from people across the globe, geneticists have reconstructed the major features of our history: our ancient African origin, migrations out of Africa, movements and settlements throughout Eurasia and Oceania, and peopling of the Americas.[11]

"Community" consent to research does not always guard the rights of subjects.

Let us say that a group gives consent now to donate genetic material to the HapMap project to be used for specific endeavors, such as the development of drug therapies directed to people from specific populations. Will that group have any control over the use of their specimens twenty years from now, perhaps for population migration research with the potential to harm the group's interests? This is one of the many unanswered questions about the project.

Even before the HapMap project, the focus on ethnic groups as subjects of genetic research has raised a great deal of concern.[12] One problem is that our current ethical paradigm of individual informed consent does not seem adequate to address situations where a whole community may be placed at risk. If a researcher needs one hundred Ashkenazi Jews to com-

plete a genetic study, only those one hundred individuals need give their consent, yet all Ashkenazim are at risk from the dangers of stereotyping, simplistic media reporting of the research results, ethical failure on the part of researchers, and so on.[13] The concerns that have been discussed to date are primarily those of discrimination: social discrimination, employment discrimination, insurance discrimination. It is easy to see that, if one group is continually trumpeted in the media in association with a host of genetic diseases, members of the group may find themselves considered less desirable as mates and employees. For this reason, there is a robust debate over whether and when it is ethically appropriate to require the consent of the group (however that might be accomplished), as well as of individuals, in genetic research in which the group will be named and may be at risk.[14]

However, this focus on possible discrimination misses another, equally important, aspect of communally based genetic research: the potential of that research to threaten or strengthen a group's communal narratives and creation stories, perhaps even a group's religious, cultural, or ethnic identity. These concerns are "fuzzier" and often more difficult to articulate than fears of discrimination, yet they are equally important. Population genetics research that seeks to "discover" a people's odyssey can be perceived as an attempt to denigrate and replace the group's own story, and the group may respond by refusing to engage in any genetic research at all.[15] Bronco Le Beau, a Lakota Sioux, says:

> The world view that we have for the Lakota is that we have always been here, we didn't migrate here, we didn't evolve here, we were created in our lands in the Pahatzapa, the Black Hills, at Wind Cave, and we reject the dominant society's world view of the migration theory. When you're talking about theories of evolution, the Lakota don't believe in that—they believe in creation. If we want to discard—I say "discard," not "discredit"—discard the dominant society view, we have the right to do that. We're people too. We're not biological specimens, we're not anthropological specimens—we're people.[16]

Genetic research can also have very practical negative consequences. For example, it could affect the group's political leverage in the larger society. Vine Deloria writes that population migration research, and the dominant story of the migration of "Native Americans" from the Bering Straits, feeds the belief that North America was a vacant land awaiting European cultivation, and that "American Indians were not original inhabitants of the Western Hemisphere but latecomers who had barely unpacked before Columbus came knocking at the door."[17] The more Native Americans are seen as "immigrants," no different in kind from the Jews who fled Eastern Europe or the English who settled the Massachusetts Bay Colony, the weaker their claims to land, sovereignty, and political and cultural distinctiveness.[18]

Sometimes one group's communal narrative can depend upon another's in complex ways. Anthropologist Thomas W. Murphy faces excommunication from the Church of Latter-day Saints because he has publicly questioned the assertion that American Indians are descended from ancient Israelites. *The Book of Mormon* describes the religious history of an ancient American civilization whose ancestors were a group of Israelites who left Jerusalem around 600 BCE. In the Western hemisphere they split into two groups, the Nephites and the Lamanites. The former were eventually destroyed, leaving the Lamanites, who are the ancestors of today's American Indians. Murphy, however, claims that there is no genetic evidence to show that any American Indians were descended from Israelites,[19] which challenges the historicity of the Church's sacred text. Thus, the Indians' history is an important element in the religious and political agendas of many other groups, and increasingly it is genetic evidence that is being used to validate competing truth claims.

While there is debate over the ethics of requiring "group consent" for genetic research, the argument for requiring that consent is probably strongest when the group's communal narrative is at stake. If any interest is held communally, by the group, surely it is the communal narrative. If some individuals in the community, without consultation with the group at large, engage in research that seriously challenges that narrative, to the point perhaps where the origin story is exploded, a communal resource is lost and may never be capable of being restored. And yet people within the group may have very different interests and stakes in the results of the research. A communal narrative that reifies one group's story may undermine that of another subgroup.

There are many groups whose communal narratives can be challenged or strengthened by the results of genetic research. In what follows, I look at two examples: the story of the Lemba of southern Africa, whose DNA strengthened their identification as Jews; and the story of Thomas Jefferson and Sally Hemings, where the DNA of their descendants corroborated some people's stories but appeared to discredit others. In both stories, a key player is the "Y" chromosome, possessed only by males. While other chromosomes shuffle and recombine their DNA, the "Y" chromosome is passed from father to son virtually intact. "That's why it was possible to match up the male Jeffersons and Hemings after so many generations. Their Y's had hardly changed at all from each other but were different from those of other families."[20]

The Lemba

The Lemba are a tribe of black South Africans who identify

themselves as Jewish. According to Lemba oral history, they have some similarities with the Ethiopian Jews, who trace their ancestry back to King Solomon and the Queen of Sheba, but the Lemba also have an account of their journey to the southern part of Africa, including a stay in a city called "Sena," whose exact location had been lost to time and consigned to legend. Lemba tradition also holds that they were the builders of the monumental ruins known as "Great Zimbabwe." The Lemba, who now number about 50,000 and who live primarily in South Africa and Zimbabwe, base their Jewish identity on a number of traditions: male circumcision, ritual slaughtering of meat and refusal to eat meat slaughtered by others, refusal to eat animals such as mice, and the ritual utterance of certain words (whose meaning has been lost) when performing circumcision and other religious acts. Their ethnic symbol is an elephant inside a six-pointed star. In anthropological jargon, the Lemba are a "Judaising African tribe."[21] Because many of these "Jewish rituals" are also practiced by Muslims, whose influence is very strong in Africa, a common explanation for Lemba culture is to define them as Muslim. But the Lemba resist that identification, insisting that they are Jews.[22]

Until recently, the Lemba claim to Jewish ancestry made little impression on their African neighbors. True, they were always seen as different in some way and often scorned and persecuted by other black Africans. The Lemba refused to intermarry or to eat with non-Lembas, which certainly contributed to the strained relations. But white Jews, who made up a small but substantial part of the South African population, ignored the Lemba bid for Jewish identity.[23]

In the 1980s, Tudor Parfitt, a scholar and world traveler who directs the Centre for Jewish Studies at the University of London, met the Lemba when he was giving a talk at a South African University. His topic was the Falashas, an Ethiopian group of Jews who had been airlifted to Israel from the Sudan. Parfitt relates that the audience was primarily white and academic, but that in the back of the room were a small group of shabbily dressed black men wearing skull caps. They introduced themselves to Parfitt as another "lost tribe," related to but distinct from the Falashas. Parfitt was intrigued by their story, and returned to interview as many Lemba as he could find. He discovered tantalizing clues to half-forgotten traditions and to ritual words that could have had Hebrew origins.

After much travel in South Africa in search of every clue he could muster to Lemba history and culture, Parfitt cautiously decided that there were "cogent" grounds for believing that the Lemba did indeed come from South Arabia, "perhaps from a town called Sena, which has preserved traditions of ancient migrations to Africa."[24] However, the Lemba claim to Jewish ancestry got a huge boost when it became possible to compare their Y chromosomes (from samples given by forty-nine Lemba men) with those of Jews whose DNA had been mapped in previous research. The result was dramatic: 50 percent of the Lemba Y chromosomes were Semitic in origin.[25] In 1997, seeking to expand on this research, Parfitt collected DNA from 136 Lemba men. "With the encouragement of the traditional leadership and the officers of the Lemba Cultural Association, the work was carried out. The project was explained at length to all the participants. Very few refused to cooperate. Most did so enthusiastically."[26] This study showed a "significant similarity" of markers between the Lemba and other peoples of Arabia, which seemed to confirm the Lemba account of their Middle East origin.[27] But the most striking results occurred when Lemba Y chromosomes were compared with those of Cohanim. In the Buba clan of the Lemba, over 50 percent of the men possessed the Cohen Modal Haplotype, almost as high a proportion as Cohen men in the Israeli study. (Among the general Jewish population, and also among the Lemba, only 10 percent have the CMH.) It is especially fascinating that the Buba, like the Cohanim, have an elevated place in their group's religious history.[28] What that means in terms of their origin story is scientifically unclear—but not the least bit unclear to the Lemba. Parfitt suggests that the most likely explanation, although one he adopts with "great caution," is that at some time in the past, Jews inhabited the South Arabian areas from which the Lemba came and the Y haplotype transmission occurred there.[29]

Genetic mapping made it easier for the Lemba to claim Jewish ancestry.

This is a dramatic, even a romantic story. Parfitt has been described as a "British Indiana Jones." The findings were popularized in the BBC series, *Origins*, and in the United States on PBS. Interestingly, in the book accompanying the *Origins* series, author Steven Jones writes:

> In the pedigree of the Lemba there is a surprise. Most of their genes—blood groups, enzymes and the like—unite them with the African peoples around them. However, those on the Lemba Y chromosome . . . have a different origin. On a family tree of the world's male lineages the Lemba are linked, not with Africans, but with the Middle East. The Lemba legend of their origin contains a hidden truth.[30]

Hidden to whom? Not to the Lemba!

An obvious and interesting question is how the Lemba would have reacted had the results shown no genetic affinities. Did they "take a gamble" and win? Or would they have

shrugged off negative results (which could never be definitive, in any case) with little damage to the power of their communal story? How did the tribal leadership weigh the possibility of results that did not support the migration narrative? How did they evaluate how the results might fall unequally on individual Lemba, depending on where they lived, their role in the tribe, how invested they were in their identity story, and so on? Parfitt reports that it was the Lemba elite who had made attempts in the past to claim kinship with South African Jews, and the elite who profited most from the media's conclusion that the genetic research affirmed their status as newly discovered Jews.[31]

We don't know the answers to these questions, but we do know that the Lemba's distinctive status as "Judaising Africans" has played into the agendas of many different peoples even before the genetic research. For Muslim proselytizers, the discovery in the 1960s of a group that practiced customs so similar to Islam sparked an energetic effort at conversion and education.[32] Parfitt early discovered that his rather innocent, determinedly apolitical venture was always in danger of being appropriated for a rather different agenda. Among racist Rhodesians, it was an article of faith that no black people could have built Great Zimbabwe. In 1972, the Rhodesian Government commissioned the editor of a racist journal called *The Mankind Quarterly* to write a book about Great Zimbabwe, entitled *The Origin of the Great Zimbabwe Civilisation*. As Parfitt describes it, the book "argues that tribes such as the Venda and the Lemba which claim connections with Great Zimbabwe have Jewish cultural and genetic traits and that their 'Armenoid' genes can only have been acquired from Judaised Sabeans who settled in the area thousands of years ago. The book's clear objective was to show that black people had never been capable of building in stone or of governing themselves."[33]

Conversely, there has long been a European tradition, in the interests of a different racial agenda, of categorizing Jews as "black" and as closely related to Africans.[34] Parfitt wonders whether the media excitement over the Lemba was "because everybody knows that Jews are not black, or. . . because at some level they are assumed to be so?"[35] Katya Gibel Azoulay, in an article provocatively entitled "Not an Innocent Pursuit," notes that genetic affinities between the Lemba and Jews are presented as startling and newsworthy precisely because Jews are persistently represented in the media as white and European, despite the reality of Jewish cultural and genetic diversity that includes many dark-skinned Afro-Asian Jews. This misrepresentation fuels the political "misrepresentation of Israel as a colonial intrusion into the brown Arab and Muslim Middle East."[36]

The advent of genetic ancestry tracing has added new dimensions to the twisted strands of different communal narratives. Just as the Mormon sacred narrative is dependent on a story of Native American descent from ancient Israelites, so the Lemba's narrative is appropriated by others as supporting material for their own communal stories. For some politically left Jewish groups, primarily in the United States, the results were taken to mean that the Lemba "are Jewish" and should be admitted forthwith into the *kelal Yisrael* (the family of Israel).[37] These groups saw the genetic results as a useful weapon against what they believe are racist and exclusivist attitudes in Israel and among Jews in general.[38] For these groups, the Lemba are the next installment in the bumpy and complex story of how Israel welcomes Jews of color.

Laurie Zoloth writes that the story of the Lemba, like that of the Ethiopian Jews before them, is "a genetic version of a classic yearning of Jewish history," the yearning for return to "the long lost home" that she considers the "ultimate mark of the Jewish condition."[39] From that perspective, the Lemba story supports a particular view of the Jewish people as a "nation" with an idealized "Home," and defines Jewishness in relation to the goal of Zionist in-gathering.

The Lemba themselves can best be described as religiously "syncretistic." Many are actively Christian or Muslim, and see no necessary conflict between their religious practices and their Jewish identity (or their Jewish practices). To this date, the efforts of Jewish proselytizers to bring normative Judaism to their newly discovered cousins has proved largely unsuccessful, although hundreds of books and ritual objects have recently been sent to the Lemba by American Jewish communities, and a number of educational missions are in train.[40] This is despite the fact that, as Parfitt notes, the genetic evidence "hardly justifies various emphatic and enthusiastic conclusions that the Lemba are indeed Jews."[41] Parfitt reports that the genetic research has grounded a new sense of Jewishness in the Lemba.[42] It remains to be seen how the strengthening of the Lemba's migration story will affect their identity in the here and now. Will they convert to normative Judaism? Will they follow their Ethiopian brethren to Israel? If so, how will the religious authorities in Israel negotiate the Jewish identity of people with no claim to maternal Jewish lineage and a religion with only a tenuous resemblance to normative Judaism? Will the Lemba remain in Africa and practice even more syncretistic forms of religion, bringing their Jewish practices more to the fore in their Christian or Muslim faiths? Parfitt relates that on the Jewish New Year of 1999, he received a letter of greeting from a Lemba tribesman, for the first time written substantially in transliterated Hebrew.[43] The letter informed him that in honor of their newly strengthened Jewish identity they would be having a big feast on Yom Kippur.[44]

Thomas Jefferson and Sally Hemings

The second example is the genetic research showing the extreme likelihood that Thomas Jefferson had a longterm sexual liaison with his slave, Sally Hemings, and was the father of her children. At first glance this might seem a rather startling example to employ here because the story does not involve the sort of research or the concerns about research that one immediately associates with genetic ethics. Yet it is especially important: it reminds us that *everyone* has creation stories, not just "primitive" folks with their "quaint" legends. It also reminds us that we exist within multilayered, overlapping identities and claim more than one creation story. All Americans share the origin story of the founding of the Republic and the writing of the Declaration of Independence, although how we stand in relation to that story may depend on our religion, our gender, our family history, and our racial background.

The majority of historians have now accepted Jefferson's paternity of at least Hemings's youngest child, Eston, and probably of her other children as well, except for Thomas Woodson.[45] Thus, the Jefferson-Hemings DNA research validated the oral history and identity of some marginalized people whose story had been excluded from our official history, and exploded the written history of the dominant culture.

Allegations of a sexual liaison with Sally Hemings surfaced as early as Jefferson's second year as president, bruited by an unfriendly reporter.[46] Hemings was a slave attached to Monticello who also acted as a companion to Jefferson's young daughter Maria when the latter joined her father in France. The two girls were close in age, and Abigail Adams, with whom the girls stayed in London on their way to the continent, remarked that Sally seemed even younger than her charge. Sally was the half-sister of Jefferson's dead wife and was three-quarters white herself. Although no pictures of her exist, she was reported as being extremely attractive, and could well have closely resembled the deceased Mrs. Jefferson. There is no question but that Hemings had five or six children, all entered as property in the Monticello records. All of her children either ran away (presumably with Jefferson's blessing, as he apparently made no attempt to retrieve them) or were freed upon adulthood or in Jefferson's will.[47]

Some of Hemings's children, or their descendants, "passed" as white. But among those who retained their black identity, the tradition of presidential paternity was strong. Lucian Truscott IV, a white Jefferson descendant, writes, "It should be made clear right here and now, that the Jefferson/Hemings story has been controversial only among white people. African Americans have long accepted the story, passing it as oral history from one generation to the next."[48] Shannon Lanier recalls standing up in his first-grade class on President's Day to announce that he was the sixth great-grandson of Thomas Jefferson. When his teacher told him to sit down and quit telling lies, Lanier's mother came to school to corroborate her son's story. "'Where is your proof?' the teacher asked. 'Where in the history books does it say that this is so?' And my mom told her that she had learned it from her mama as her mama had learned from hers, and so on, from lips to ears, down through the generations."[49] Just as in the Lemba's story, the genetic "discovery" was simply accepted fact by the group that carried the oral history.

Robert Cooley, a retired U.S. Army lieutenant colonel who claims to be Jefferson's descendant through Hemings's first child, Thomas Woodson, recalls hearing about his "special" identity from his grandfather, when he was ten years old. "Sally was a very articulate woman. . . She was very educated. She told us. She told her son Thomas, and Thomas told others in his family. And so, in my family, I have the benefit of 200 years of consistent, solid oral history. . . Those historians don't know. They don't know what I know. And they are making their judgment on what someone else has written. They don't have the benefit of the oral transmission."[50]

DNA testing in 1998 compared Y-chromosomal haplotypes from five male descendants of Field Jefferson, a paternal uncle of the president, with those of male descendants of Hemings's first and last sons. Because all of Jefferson's "white" descendants were the offspring of his daughter, the Jefferson-Hemings match depended on obtaining a DNA sample from a descendant of Field Jefferson, Thomas's paternal uncle.[51] The genetic research was initiated by Eugene Foster, a pathologist who became interested in the Jefferson-Hemings question. Foster approached the Thomas Woodson Family Association but they refused to cooperate without certain assurances that Foster either could not or would not give, such as independent testing of the blood samples. Foster then circumvented the association by finding Woodson descendants who agreed to cooperate.[52]

The DNA testing can never prove conclusively that even one of Hemings's children was fathered by Jeffer-

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son. On the most skeptical view, all they show is that Sally's son Eston was fathered by either Thomas himself or a close relative. Corroborating evidence is that Thomas, who was away from home for long periods of time, was resident at Monticello nine months before the births of each of the Hemings children; but this can also be explained by the theory that, when the master of Monticello was at home, other of his male relatives were more likely to be visiting.[53] The eminent Jefferson historian Joseph Ellis was scornful of the Hemings connection before the DNA testing, calling it "a tin can that's been tied to Thomas Jefferson's tail and has rattled through the ages and pages of history" and claiming that, if it were a legal case, Jefferson would be acquitted.[54] After the DNA results, he said that the case for Jeffersonian paternity had been proved "beyond a reasonable doubt."[55]

At Monticello, guides had already been incorporating more information about the slaves who built and worked the plantation. After 1998, they began to tell visitors of the strong likelihood that Jefferson had fathered at least one of the Hemings children.[56] On the other hand, the majority of members of the Thomas Jefferson Family Association have balked at acknowledging their new cousins. President George W. Bush, at a White House ceremony on Jefferson's birthday, invited descendants of both Jefferson's official and unofficial families and diplomatically welcomed "all the descendants of Thomas Jefferson who are here."[57]

The Jefferson-Hemings saga showcases all the issues that can surface when a communal narrative is put to the genetic test. First, many different narratives are involved in the same (or is it the same?) story. Those who trace their lineage to Jefferson's daughter are now being called upon to reevaluate their family history and to broaden their concept of who belongs in their family. For the Hemings descendants, the news is mixed. Ironically, it is the descendants of Hemings's possible first son, Thomas Woodson (whose very existence is in doubt), who have the strongest oral tradition of presidential paternity, but it is their line that the DNA evidence conclusively rejects. Not surprisingly, not all of Woodson's descendants accept this result. Michelle Cooley Quille, one of the Woodson line, says, "Look who was positive. Eston's line. Eston was one of the last kids. Eston comes when Jefferson was an old man. . . So we can go around and around about what Dr. Foster's team's motivations might have been, and I can't say that the test's not accurate. If they had taken DNA from my brother, then I would believe it as representing me, but they didn't. The point is, *we know who we are*."[58]

Meanwhile, it is Jefferson's paternity of Eston that the DNA evidence establishes with the greatest certainty, but Eston's descendants have long taken on white identities. After Jefferson's death, Hemings's remaining sons migrated to southern Ohio (son Beverly and a daughter Harriet had already "run away" and passed into the white world). One-eighth black, the brothers were fair, with the characteristically Jefferson red hair and gray eyes. Madison Hemings remained within the black community, but Eston moved to Wisconsin, where he changed his race to white on the census. The family broke with their black roots and ended up on the social registry.[59] Julia Jefferson Westerinen now knows that her father knew of the connection but kept it secret. It was Westerinen's brother who volunteered his blood sample.[60] Julia reports being delighted with her new family connections, and registered her race as black on the most recent census.[61]

In some cases, the news caused painful revelations and reunions that were simultaneously joyous and wary. Amalia Cooper, whose father had hidden his black family connections all his life, decided to contact her black second cousins, part of the extended black Hemings clan that settled in Ohio. Amalia and her sisters were warmly received, but there are obvious tensions in this new family grouping which has both "black" and "white" members, depending on how they choose to identify themselves.[62]

Thus for every member of the Jefferson family, the DNA evidence strengthens an existing narrative, changes completely what the person had thought was her family story, or challenges an official account. Julia Westerinen said that she had "gained a lot" from the DNA results. "Our family is like a sample family that was deeply divided and then came together. . . So think of what an example we can set for America."[63] The reactions of these many different players bring to mind Paul Brodwin's warning that interpreting the results of genetic research involves more than just judging the credibility of the science. One must also compare the worth of genetic knowledge against "other kinds of claims to authentic identity and group membership," such as oral history, group cohesion, and the redressing of historical injustice.[64]

And what about the rest of us, whether our families came over on the Mayflower, arrived just last week, came here in chains, or have been here since before written history, we who situate ourselves in the stream of American narrative, where Thomas Jefferson is our political ancestor and Founding Father, the author of our most sacred communal text, and the architect of a sacred pilgrimage site? To quote historian Richard Brookhiser, "if Americans commit parricide on [Jefferson], they commit suicide."[65] George Will writes:

> A late-20th century America is concerned about its identity, and it's come to be aware of the fact that we are a creedal nation—and he gave us our creed. He made it accessible. A lot of nations emerge from the mists of history and their basic identity is tribal, it's rooted in groups. Ours is rooted in assent, an assent to certain propositions. We are, as Lincoln said. . ., "a nation dedicated to a proposition." Jefferson wrote the proposition.[66]

Do we understand ourselves differently as Americans if we accept the evidence that Jefferson fathered Hemings's children? Ellis likens the search for the historical Jefferson to the pursuit of the historical Jesus and argues that what is important is not the historical figure of Jefferson but "what we've made of him."[67] Some would point out that the important facts about Jefferson and slavery were already well known, including the damning fact that he almost never freed slaves and often sold them off, even dividing families to do so, in order to support his extravagant lifestyle. George Washington, in contrast, freed all his slaves, as did one of Jefferson's cousins and one of his neighbors. After all, even if Jefferson fathered none of Hemings's children, they were still his nieces and nephews twice over; the fact that Sally was the daughter of John Wayles, Jefferson's father-in-law, was never in question, and if Jefferson was not their father, one of his close relations surely was.[68]

For some critics, it is Jefferson's hypocrisy that is most troubling. Ellis says, "[T]he real issue . . . is, how could this man who was living in the midst of what is effectively a bordello at Monticello where relations between blacks and whites were going on all the time, whether or not he himself was involved, how could he be presiding over this and simultaneously believe in the values associated with the Declaration of Independence?"[69]

Group Identity and Group Consent

The Lemba's narrative stretches back to King Solomon; the Jefferson story is barely two hundred years old. In both cases, the communal narratives span time and space to touch many more people than the researchers probably imagined. As a Jew, I wonder if this research shows that the Lemba and I are cousins; as an American, I ponder what this revelation about Jefferson means to my creation story. One fascinating aspect of this inquiry into genetic research on specific communities is the way in which "group identity" can be characterized as political, racial, ethnic, historic, religious, geographic, and more.

Exploring the potential of genetic research to strengthen, question, explode, or destabilize communal narratives (perhaps at one and the same time) adds depth to the current concern over ethical recruitment of subjects for genetic research. For fears about discrimination, there is some power to allay anxiety by passage of protective legislation, and also by better public education. But when the fear is damage to identity, what remedy exists?

The natural response is to call for more and better community consultation, perhaps even a requirement for community consent. It is telling, after all, that the results in the Jefferson-Hemings case were achieved with DNA gathered from only fourteen people, some of whom acted in defiance of family wishes. Many researchers who have worked with communities are adamant that researchers who are not part of the community often fail to "appreciate community-specific risks. . . even once they have been identified for them," and that therefore community involvement and consultation are essential.[70]

Respect for persons, a pillar of research ethics, requires not only respect for the individual research subject, but arguably also for the group whose characteristics are the object of the study. Without some measure of respect for the "group," the interests of individuals themselves will not be met. Individuals have interests that they can protect only through group action, and individuals have interests in the well-being of groups with which they identify.[71]

But "community consent" begs the question, *Which* community? Should the descendants of Martha Wayles Jefferson have had a say in whether the descendants of Sally Hemings should have their DNA matched with Jefferson's? As the children of Eston and Madison Hemings press their claims, grounded now on the genetic evidence, should they consider the ways in which they may be weakening the claims of the children of Thomas Woodson? Perhaps all of us Americans should have had a vote in the matter, since it is our common heritage that is at stake.

Turning to the example of the Lemba, there are presumably people in the tribe whose status and role in the community is dependent on continuing its Christian or Muslim practices; these people will perhaps be disadvantaged by the strengthening of a genetically driven movement toward a less syncretistic Jewish practice. Non-Lemba women who married into the tribe (and no group is completely endogamous) may feel threatened by the tribe's increasing identification with a matrilineal religion that would call into question their children's membership. Charles Weijer and Ezekiel Emanuel have created a sophisticated table that attempts to weigh community characteristics to come up with a "spectrum of cohesiveness" for evaluating the efficacy of community consent.[72] But where a strong and cohesive community does exist, community consultation between the researcher and the recognized community authorities will inevitably privilege the agenda of the community elite.

A full evaluation of genetic research must explore its effects on communal narratives (and group creation stories).

Morris Foster points out that, even in the absence of community consensus, and even when a full discussion may "exacerbate pre-existing social divisions," community involvement can be valuable in considering a study's implications.[73] Perhaps that is the best we can do. Certainly, a full appreciation of all the possible risks and benefits of participation in genetic research must include exploration of the possible significance of that research for the group's creation stories and communal narratives. Today's descendants of Hemings and Jefferson, especially those for whom the results of genetic inquiry were unexpected, show how profoundly their lives have been affected by the outcomes of this research.

A result as important as this in the lives of individuals cannot be ignored, and deserves to be considered with the same seriousness as concerns about stigma or discrimination. As Barry Lopez says, "The stories people tell have a way of taking care of them . . . Sometimes a person needs a story more than food to stay alive. That is why we put these stories in each other's memory. That is how people care for themselves."[74]

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In Memoriam: John C. Fletcher

John C. Fletcher, who died May 27, 2004, was a pioneer in bioethics. In 1967, while pursuing his doctorate at Union Theological Seminary on the ethics of clinical research, he published an article on "Human Experimentation: Ethics in the Consent Situation" in *Law and Contemporary Problems*. As the bioethics movement gained momentum, he became a founding fellow of The Hastings Center.

In the late 1960s, John taught at Virginia Theological Seminary before founding an experimental theological seminary in Washington, D.C. In 1977, he became the first chief of the Bioethics Program in the Clinical Center at the National Institutes of Health. He joined the faculty of the University of Virginia in 1987, where he established and directed the Center for Biomedical Ethics and taught until his retirement in 1999.

John's several books and numerous articles made valuable contributions to bioethics, both in providing empirical data and in arguing for particular policies and practices in research, death and dying, reproductive technologies, and genetics. However, his main influence stemmed from his leadership and entrepreneurial activities, especially in promoting bioethics as an institutional service for addressing ethical issues and resolving moral problems, with the aim of helping medical research and health care institutions carry out their missions within appropriate ethical constraints.

From the early days of his work in research ethics, John was impressed with the Institutional Review Board as a mechanism for bringing impartiality into the planning and conduct of clinical research. He also advocated hospital ethics programs, including ethics committees, ethics consultation services, and ethics education. He believed that these programs could help protect the rights and well-being of research subjects and patients and also protect institutions from "ethics disasters." In his view, institutional ethics services should be both proactive and responsive. His role in founding the Society for Bioethics Consultation, later merged into the American Society for Bioethics and Humanities, reflects this focus.

John also promoted institutions for "public bioethics"—that is, ethics commissions as forums for deliberating and providing guidance about emerging bioethical issues of concern to the society at large.

John loved the field of bioethics, including its intricate scientific and clinical issues, and shared this love with others, believing that bioethics could make a real difference for research subjects and patients. At heart he was a reformer, seeking to shape institutional policies and practices, and he pursued his mission vigorously and indefatigably. For many, he was also a highly-valued mentor. In 2000 the American Society of Bioethics and Humanities honored his contributions to the field by bestowing on him its Lifetime Achievement Award. We will greatly miss this bioethics pioneer, colleague, and friend.

James F. Childress, University of Virginia

Franklin G. Miller, National Institutes of Health

The opinions expressed are those of the authors and do not necessarily reflect the position or policy of the National Institutes of Health, the Public Health Service, or the Department of Health and Human Services.