

In the Amazon, Giving Blood but Getting Nothing

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KYOWÃ, [Brazil](#) — As the Karitiana Indians remember it, the first researchers to draw their blood came here in the late 1970s, shortly after the Amazon tribe began sustained contact with the outside world. In 1996, another team visited, promising medicine if the Karitiana would just give more blood, so they dutifully lined up again.

But that promise was never fulfilled, and since then the world has expanded again for the Karitiana through the arrival of the Internet. Now they have been enraged by a simple discovery: their blood and DNA collected during that first visit are being sold by an American concern to scientists around the world for \$85 a sample.

They want the practice stopped, and are demanding compensation for what they describe as the violation of their personal integrity.

“We were duped, lied to and exploited,” Renato Karitiana, the leader of the tribal association, said in an interview here on the tribe’s reservation in the western Amazon, where 313 Karitiana eke out a living by farming, fishing and hunting. “Those contacts have been very injurious to us, and have spoiled our attitude toward medicine and science.”

Two other Brazilian tribal peoples complain of similar experiences and say they are also seeking to stop the distribution of their blood and DNA by Coriell Cell Repositories, a nonprofit group based in Camden, N. J. They are the Suruí people, whose homeland is just south of here, and the Yanomami, who live on the Brazil-Venezuela border.

Coriell stores human genetic material and makes it available for research. It says the samples were obtained legally through a researcher and approved by the [National Institutes of Health](#).

“We are not trying to profit from or steal from Brazilians,” Joseph Mintzer, executive vice president of the center, said in a telephone interview. “We have an obligation to respect their civilization, culture and people, which is why we carefully control the distribution of these cell lines.”

Like a similar center in France that has also obtained blood and DNA samples of the Karitiana and other Amazon tribes, Coriell says it provides specimens only to scientists who agree not to commercialize the results of their research or to transfer the material to third parties.

The indigenous peoples of the Amazon are ideal for certain types of genetic research because they are isolated and extremely close-knit populations, allowing geneticists to construct a more thorough pedigree and to track the transmission of illnesses down generations.

The practice of collecting blood samples from Amazon Indians, though, has aroused widespread suspicions among Brazilians, who have been zealous about what they call “bio-piracy” ever since rubber seedlings were exported from the Amazon nearly a century ago. The rise of genome mapping in recent years has only exacerbated such fears.

Debra Diniz, a Brazilian anthropologist, argues that the experience of the Karitiana and other tribes shows “how scientists still are ill prepared for intercultural dialogue and how science behaves in an authoritarian fashion with vulnerable populations.”

The core of the international debate that has emerged here, though, has to do with the concept of “informed consent.” Scientists argue that all the appropriate protocols were followed, but the Indians say they were deceived into allowing their blood to be drawn.

“This is sort of a balancing act,” said Judith Greenberg, director of genetics and developmental biology at the National Institute of General Medical Sciences, part of the National Institutes of Health. “We don’t want to do something that makes a whole tribe or people unhappy or angry. On the other hand, the scientific community is

using these samples, which were accepted and maintained under perfectly legitimate procedures, for the benefit of mankind,” she said.

The Indians themselves, however, respond that at the time the first blood samples were drawn, they had little or no understanding of the outside world, let alone the workings of Western medicine and modern capitalist economics.

Francis Black, the first researcher to take blood samples here, died recently, so it is impossible to obtain his account. But officials of the National Indian Foundation, or Funai, the Brazilian government agency that supervises tribal groups, said that his presence on the reservation here violated procedures specifically aimed at protecting Indians from outsiders.

“We would never have authorized such a thing,” Osmar Ribeiro Brasil, who has worked at the agency’s regional headquarters in Porto Velho since the 1970s, said of the blood collection. “There is no record of any research permission request either here or at our headquarters in Brasília.”

For the reporting of this article, all the required procedures were followed. Funai authorized the visit here and sent an official to accompany a reporter and a photographer. But that official did not sit in on the interviews here or coach the Indians in their responses.

In the case of the 1996 expedition, permission to enter the reservation was obtained, but only to film a nature documentary, Funai officials said. Once on the reservation, however, a Brazilian doctor accompanying the film crew, Hilton Pereira da Silva, and his wife began conducting unauthorized medical research, Funai officials and residents of the reservation said.

“If anyone is ill, we will send medicine, lots of medicine,” is what Joaquina Karitiana, 56, remembers being told, which soothed her worries. “They drew blood from almost everyone, including the children. But once they had what they wanted, we never received any medicine at all.”

Dr. Pereira da Silva was not available for comment. But in a statement that he issued in response to complaints about his work, he said he had explained the purposes of his research “in accessible language” and had promised that “any possible benefit of any type that results from research with this material will revert in its entirety to those who donated.”

As a result of the legal pressures that the tribe and Funai have brought, Brazilian institutions that had collected blood samples have returned them to the tribes. But entities abroad have resisted, saying both that they acted properly and that there are no profits to be shared with the Indians.

“They want money, and we have not made any money,” Mr. Mintzer of Coriell said. “I don’t know of anyone who has made any money from this.”

The Karitiana say that includes them. Antonio Karitiana, the village chief, said that health care, sanitation and housing were precarious, and that transportation was deficient. Any money obtained from Coriell or a lawsuit would be invested “for the benefit of the entire community,” he said.

“We don’t want that blood back, because it is contaminated now,” said Orlando Karitiana, 34, a tribal leader. “But these blood samples are valuable in your technology, and we think that every family that was tricked into giving blood should benefit.”

The religions of some other tribal groups, however, regard human tissue as important or nearly sacred. The Yanomami, for example, say they want the blood samples returned to them intact.

“A soul can only be at rest after the entire body is cremated,” said Davi Yanomami, a leader of the group. “To have the blood of a dead person preserved and separated from the remainder of the body is simply unacceptable to us.”

But Francisco M. Salzano, one of Brazil’s leading geneticists, with more than 40 years of experience in the Amazon and dealing with

indigenous peoples, argues that it is acceptable to brush aside such concerns.

“If it depended on religion and belief, we would still be in the Stone Age,” he said in a telephone interview from his office at the Federal University of Rio Grande do Sul.

“None of these samples have been used in an unethical manner,” Dr. Salzano added. As for the question of informed consent, he added, “That is always relative.”