

## APPENDIX I

*(translated from the Portuguese original)*

Document N° 115/2002/CaDIM/MPF

Brasilia, March 7, 2002

Subject: Yanomami blood

Dear Professor,

We recently learned that, during the 1960s, American researchers collected blood from the Yanomami Indians, whose territory is located on both sides of the Brazilian-Venezuelan border. The blood samples were deposited in the Pennsylvania State University and the University of Michigan at Ann Arbor. We would appreciate your responding to the following questions:

- 1) Are Yanomami blood samples still stored in laboratories at these universities?
- 2) If so, how many samples are there and how are they being conserved?
- 3) What was the source of these samples?
- 4) What documents exist that attest to the procedures used for obtaining informed consent at the time the blood samples were collected?
- 5) When were the samples collected in Brazil? Is there documentation pertaining to official authorizations granted by Brazilian institutions for research projects allowing these samples to be collected?
- 6) What is the current juridical-administrative status of the custody of these samples by these university laboratories?
- 7) What is the connection between such custody and the use of Yanomami blood samples in the Human Genome Diversity Project (HGDP), as well as the relation between this project and official agencies of the United States government, such as the U.S. Department of Energy?
- 8) Have these samples been reprocessed to extract their DNA, or have they been used in new research projects?
- 9) Are there documents stating whether informed consent was obtained for undertaking new research projects with these samples?
- 10) Have Yanomami blood samples or DNA been released (through donations or sale) for research or other purposes by other public or private laboratories? What type of contract was involved? Which laboratories?

Attached is a copy of the Brazilian Constitution, which attests to the legitimate authority of the Federal Public Ministry to carry out this investigation.

Cordially,

ELA WIECKO VOLKMER DE CASTILHO  
Assistant Attorney General of the Republic of Brazil  
Coordinator, Sixth Chamber of Coordination and Review,  
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April 8, 2002

Ms Ela Wiecko Volkmer de Castilho  
Deputy Attorney-General of Brazil  
Ministerio Publico Federal  
6ª Camara de Coordenacao e Revisao  
Brasilia, Brazil

Dear Ms Volkmer de Castilho:

Here are answers to your request for information about Yanomami blood samples. I am also in regular correspondence with US anthropologists who are working directly with the Yanomami and their representatives in Brazil about this matter.

1. I have samples in my laboratory that I believe were obtained from Yanomami. There are sets of samples in the University of Michigan (Ann Arbor, Michigan), at Emory University (Atlanta, Georgia), and I believe in US National Institutes of Health National Cancer Institute (NIH/NCI, Bethesda, Maryland). I have communicated with the scientists who have these samples to tell them that questions are being raised about the samples.
2. The samples have been frozen since they were collected. I do not know the exact number but there are about 3,000 individuals represented.
3. I was not involved in any trips to South America or the collection of the samples. According to my understanding, most of these are from Venezuela. I do not know how many samples were collected within Brazilian territory.
4. I believe that at the time the samples were collected, formal informed consent procedures of the kind that scientists around the world now use had not been developed. I do not know exactly how Dr Neel's group explained his request for blood and other biological samples to the Yanomami. But he was concerned about the ethics of his work, and I think he believed that his procedures were fully consistent with ethical practice at the time. My understanding is that, through translators, he explained his intentions in terms he thought would make reasonable sense to the Yanomami, given the technical nature of the science. My understanding is that participation was voluntary and that the samples were obtained in part by agreement to exchange samples for goods of value to the Yanomami, and that Dr Neel and his group provided at least some medical care to the population, including vaccinations and other treatments.
5. I cannot answer these questions directly because Dr Neel has died and I do not have his papers or records. To the best of my understanding, the samples were collected in the period from 1966 to the early 1970s, but I do not know the exact dates. Dr Neel worked with scientists from Brazil and Venezuela, and he had the permission and cooperation of the Brazilian and Venezuelan

governments to collect the samples and to bring them to the United States for study. On at least some trips he was accompanied by Brazilian government officials, including a military official, to ensure that what was done was consistent with what had been approved. He needed government permission to get equipment into and samples out of the country to bring them to the United States. For information about Brazilian permissions perhaps you should contact Dr Francisco Salzano, of the Mauro Federal University of Rio Grande do Sul, who I think was Dr Neel's main Brazilian scientific collaborator. Dr Salzano could probably tell which office of the Brazilian government was involved and approved the work.

6. The universities where the samples are stored presumably have legal control of the samples. The NIH/NCI (US Government) would have this control of the set of samples in their laboratory.

7. There is no connection to the Human Genome Diversity Project that I know of, and I do not know if there is any connection between the US Government and the HGDP. I am no longer involved in the HGDP but I think it has not ever been formally funded as a single project.

8. My laboratory developed technical procedures by which DNA can be extracted from samples like these, to make it possible for new research to be done without using up all the sample material. But we are not doing any research with the samples at the present time.

9. We have been working under the belief that the original consent would still apply because the kinds of work we were doing merely applies new technology to questions similar in nature and objectives to what was originally done. As far as I know, the original consent was oral and did not involve documents, but placed no time limit on their use.

10. To my knowledge there has not been any sale of any kind related to these samples. As far as I know, no financial profit has been made from these samples.

Yours truly,



Kenneth M Weiss, PhD  
Evan Pugh Professor of Anthropology and Genetics