

Center for a
P U B L I C Anthropology

February 17, 2006

President Graham Spanier
Office of the President
201 Old Main
The Pennsylvania State University
University Park, PA 16802

Aloha President Spanier,

While apologizing for adding another concern to the many I am sure you have to deal with each day, I would draw your attention to a matter that has significant implications for Penn State. At issue are the blood samples of roughly 3,000 Yanomami stored at your university in Professor Ken Weiss's laboratory. The Yanomami are an Amazonian Indian group living along the Brazilian-Venezuelan border. According to Prof. Weiss, Penn State has legal control over these samples (Prof. Weiss's letter dated April 8, 2002). Both the Yanomami and Mr. Mauricio Fabretti, a Deputy Attorney General of Brazil, have requested the return of the blood samples. To date, Prof. Ken Weiss and Dean Susan Welch have refused.

I have included various documentation so you can judge for yourself the facts of the case. But let me provide some background so you can more readily make sense of the material.

The blood samples are part of a heated controversy regarding the research carried out by Professor Napoleon Chagnon and the late Professor James Neel. One important question raised is whether Prof. Neel, who extensively collected blood samples in 1968, followed proper informed consent procedures. That issue has not been resolved. But what is clear is that the 1968 blood was collected under misleading circumstances. According to Prof. Chagnon, who was the key translator and interface between Prof. Neel and the Yanomami:

for a year before Neel's arrival and during the collection phase he told the Yanomamö [a variant pronunciation/spelling of Yanomami] in all the villages to be sampled that Neel's team wanted to examine their blood in order to determine whether there were things that indicated whether or not they had certain kinds of diseases, especially *shawara* (*epidemic diseases*) and that this knowledge would help treat them more effectively if they became ill." [quoted by Prof. Ray Hames, a student of Prof. Chagnon, from a conversation he had with Prof. Chagnon on March 18, 2001, in *Yanomami* 2005:170-71].

There is no doubt Prof. Neel provided significant medical assistance to the Yanomami during his 1968 stay. But, just as clearly, there is no record of the information Prof.

Chagnon indicated would be provided back to the Yanomami (and/or the medical authorities assisting them) if the Yanomami donated blood of ever having been provided by Prof. Neel and his research team following the 1968 expedition.

It is sometimes argued that a pre-1968 sampling of blood did prove beneficial in the treatment of Yanomami during a 1968 measles epidemic. That is correct. But the 1968 Neel expedition – which collected the largest number of Yanomami blood samples and whose biological specimens constitute the core of the Penn State collection – never provided the promised medical benefits. Yanomami were clearly misled in this regard.

As the enclosed material indicates, there has been correspondence between two Brazilian Assistant/Deputy Attorney Generals (Ela Wiecko Volkmer de Castilho and Maurício Fabretti) with Prof. Weiss and Dean Welch regarding this matter. While this correspondence has been professional in tone, some might perceive the spirit of some of the latter's letters as either deceptive or rude. This is because the correspondence originating from your university repeatedly acknowledges that, in principle, the university is open to returning the blood. But then some problem is raised that makes it nearly impossible to do so.

Take, for example, the recent letter by Dean Susan Welch, dated January 3, 2006 in response to Mr. Maurício Fabretti's question "whether your institution might agree to willingly return those blood samples . . . to the Yanomami who made the . . . request" (from his letter dated July 29, 2005). Mr. Fabretti enclosed sections from the Brazilian constitution to affirm the Attorney General's legal authority to represent the Yanomami in this matter. Dean Welch writes in reply, "it is the University's intention to fully cooperate with all relevant government authorities regarding this matter and to respect and honor all applicable laws, regulations, and cultural norms." But she then goes on to state:

We believe it is important that all potential "stakeholders" (any persons with a legal interest in, or obligation regarding any of the samples) are in full agreement with any plan to transfer custody of any of the samples in Penn State's possession to any third party. At a minimum, we anticipate that this will involve both the Brazilian and Venezuelan governments, but we also seek confirmation from those governments as to the interests of any other local recognized governing authorities, and that all such authorities have expressly approved the return of all samples. This would include any involved tribal councils, elders, and similar tribal authorities.

In this light, we would like to inquire with you whether you have been able to develop a proposed protocol for the return of the samples that ensures the interests of all relevant stakeholders have been addressed? If so, we believe it is essential that such a written document would be expressly approved by all such stakeholders. Only in this fashion could the University ensure that it has appropriately discharged any responsibilities it may have to each and every interested party.

We look forward to working with you in identifying and corresponding with these stakeholders.

Dean Welch expresses limited familiarity with the Yanomami and the Brazilian constitution. She frames the matter in terms that, presumably, feel comfortable to her as an American – terms that allow Penn State to retain the blood samples. Professional and common courtesy assume one will address the problem in terms that are also meaningful to the Yanomami and/or the Brazilian authorities that constitute their legal guardians under the Brazilian constitution. To quote Article 129, especially section V, of the Federative Republic of Brazil's constitution: "The following are institutional functions of the Public Prosecution . . . V – to defend judicially the rights and interests of the Indian populations."

Dean Welch pointedly ignores the Brazilian constitution in her reply and expresses limited understanding of current forms of social organization among the Brazilian Yanomami (such as the creation in 2004 of the Hutukara Association). One might, in fact, wonder if she is striving to subvert Mr. Fabretti's legally constituted authority under the Brazilian constitution by inserting herself as a defender of Yanomami interests when she writes: "we believe it is essential that such a written document be expressly approved by all such stakeholders" and "we look forward to working with you in identifying and corresponding with these stakeholders." Is she saying that she, rather than Mr. Fabretti and the Brazilian government, will have the final (or even partial) say in deciding who the proper stakeholders are and whether the "stakeholders'" correspondence indicates the blood should be returned? She offers no financial or administrative assistance in this matter. It is not even clear she speaks for you, the President of Penn State. She simply inserts herself between the Yanomami, with whom she is unfamiliar, and Brazilian authorities presuming, in some sense, to represent Yanomami interests.

Please note the position by Dean Welch contrasts sharply with the position of Dr. Joseph Fraumeni, Director of the Division of Cancer Epidemiology and Genetics at the National Cancer Institute. To quote from his recent (enclosed) letter: "We are willing to return the specimens to Yanomami representatives from Brazil and Venezuela. We are happy to work with you and Yanomami representatives from each country to arrange a safe and successful transfer." There are none of the qualifications and qualms present in Dean Welch's letter.

The seeming stonewalling by Penn State officials explains why a number of American anthropology students have become involved in the issue. The students seek to bring this problem to a wider public. The approximately 800 students from seven schools who participated recently in writing letters on this issue had the same information to examine as you have (with the exception of Mr. Fabretti's recent letter to Prof. Weiss and Dean Welch's letter to Mr. Fabretti). The students were free to choose between supporting Prof. Weiss's and Dean Welch's position of keeping the blood samples at Penn State or Mr. Fabretti's and the Toototobi Yanomami's position of returning the samples back to the Yanomami. While some students suggested keeping the samples at Penn State to facilitate medical research, the great majority supported returning the blood to the Yanomami. The two enclosed letters – from Ms. Anne-Marie Rick (of the University of Notre Dame) and Mr. Charlie Brummitt (of the University of Wisconsin) – were judged by students in the project as best articulating their general views. Mr. Brummitt discusses the difference between

good and bad science and that “the tradeoff for studying the samples further . . . is that anthropology loses its place on the high pedestal of morality and loses valuable trust with people outside the discipline.” Ms. Rick observes the line between research and morality was breached in the case of the blood samples. (Ms. Rick emphasizes the Toototobi Yanomami of Brazil in her letter because, as the enclosed material indicate, the Toototobi Yanomami have been quite vocal in demanding the return of their deceased relatives’ blood.)

Two additional facts might prove useful to you. First, the Yanomami blood samples are not currently being used in any research at Penn State nor have they been for some time. As Prof. Weiss indicated in his letter to Ms. Ela Wiecko Volkmer de Castilho (dated April 8, 2002), “we are not doing any research with the samples at the present time.” Dean Welch makes the same point in her recent letter. Second, the Yanomami want the blood back because according to Yanomami belief – a belief shared among diverse sub-groupings – a deceased individual’s remains must be destroyed through a complex ritual so the deceased’s soul can live happily “on the back of the sky” (to quote Prof. Bruce Albert who has extensively studied them) as well as not come back to haunt or threaten the living. Yanomami want their deceased relatives’ blood back, in other words, for very practical reasons: to help their relatives find happiness after death and to protect themselves from harm.

As far as anyone knows, the Yanomami were never informed that their blood samples would be kept for more than 30 years in refrigerators in the United States. Knowledge that this might occur would have upset the Yanomami and, quite likely, prevented them from donating blood. Thus, the drawing of blood from the Yanomami in 1968 was not in keeping with the “informed” nature of informed consent. The Yanomami were not informed that their blood would remain stored in refrigerators well after their deaths. It is particularly telling that, despite years of controversy regarding the issue of informed consent, no one has ever challenged this point.

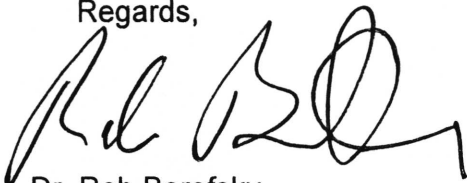
Students from additional universities are awaiting your response. Their hope is to mobilize a letter-writing campaign to thank you for positively resolving the problem – forwarding to the Brazilian government and the Yanomami the appropriate blood samples stored at Penn State. If that proves not to be the case – given the problems encountered with Penn State to date that unfortunately is a possibility – then the students will publicize the problem still more widely. Tentative plans call for writing letters to Governor Edward G. Rendell and members of the Pennsylvania General Assembly during the current legislative/appropriations process. Please do not take this as a threat. It results from the frustration of being repeatedly stonewalled by people under you preventing a just and honorable resolution of the issue. Instead of acknowledging the Yanomami and the Brazilian Deputy Attorney General’s legal responsibilities to them under the Brazilian constitution, they have sought to hold on to the Yanomami blood samples even though they were obtained under dubious circumstances and are not being used in research at Penn State. Others need know whether Penn State condemns this practice not only in words but

in clear, concrete actions. Certainly, the National Cancer Institute, as Dr. Fraumeni's letter indicates, wants to set the matter right. Dr. Fraumeni wants to return the blood.

I appreciate you are a busy man and, hence, I hesitated to bring this matter to your attention. But I hope you recognize the concern of many people, beyond Penn State, with how Penn State resolves this matter. In a democracy such as ours, justice not only resides in appointed officials but also in the wisdom of its citizens. The thousands of students involved in this project wish to publicize the matter as widely as possible. Here is a chance, in the words of Ms. Rick, to "uphold the ethical standards of your university" and "show the world the importance you attach to such ethical standards and to right a wrong."

I look forward to your response and hope this matter can be positively resolved in the immediate future. Thank you.

Regards,

A handwritten signature in black ink, appearing to read 'Rob Borofsky', written in a cursive style.

Dr. Rob Borofsky,
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December 9, 2005

President Graham Spanier
Office of the President
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University Park, PA 16802

Dear Dr. Spanier,

I have recently become aware of the controversy concerning the Yanomami blood in Penn State University's possession and I am writing to you on behalf of the Yanomami people. As president of the University, I understand that this is a particularly difficult situation for you since the acquiring of the blood occurred prior to your tenure as president. However, this international disagreement over respect for the dead and medical relevance has challenged the academic community at Penn State. As a result, you play an instrumental role in representing your university and have the authority to end this controversy.

As documented in letters from three Toototobi Yanomami Yanomami leaders and requests made by the Hutukara Associacao, the Toototobi Yanomami want the blood taken from the relatives in 1968 returned for ceremonial destruction. Although the Toototobi Yanomami originally gave consent for the blood to be taken, they were led to believe that it was to help trace diseases and eventually provide cures and medicines for the Yanomami people. They did not realize that it would be brought to an institution where it would remain in a freezer for the next 38 years. Although the standard of ethics was not well defined for anthropologists during 1968, we are at a time in history when the ethical choices we make define who we are as a society. We are, therefore, obligated to abide by a higher standard of ethics than those who came before us. In this controversy, we must examine the cultural, ethical, and practical elements and be prepared to make a choice that may injure pride but will right a longstanding wrong.

The Toototobi Yanomami are a spiritual people that believe it is sacrilegious for the blood of their ancestors to remain in this world after their passing. They believe in ceremonial rights to destroy the blood that allows their ancestors to rest in peace. The Toototobi Yanomami blood taken by Dr. Neel in 1968 was given with consent of the people. Promised medicines and cures for diseases, the Toototobi Yanomami readily handed over their blood but were under the misconception that the blood would be destroyed after initial examinations. Almost forty years later, the children of these Toototobi Yanomami realized that their deceased relatives have not been properly honored in death. Now they cry out for justice and peace for the Toototobi Yanomami

that have passed on.

Although the blood has been stored for over 38 years, no published data or medical relevance has benefitted the Yanomami during its time at Penn State despite Dr. Chagnon's promise that it would (according to a statement made by Ray Hames – see Yanomami, 2005:170). The only research involving the 1968 Yanomami blood samples has focused on academic questions relating to genetic diversity and migration patterns among various North American groups. The blood was not originally taken for this purpose, and therefore, on principle, the Toototobi Yanomami were deceived.

I understand that the Yanomami blood could in fact prove future medical relevance about diseases and characteristics existing among the South American Indians. Currently, however, there is no researcher at Penn State that is studying this blood. If a researcher decided that a study of Yanomami blood was relevant, then new blood that more accurately reflects the current population could be collected with the consent of the people and used in an active study.

To refuse the Toototobi Yanomami request for the return of their relative's blood is an insult to their culture and to the values of anthropology. As academic professionals, we are obligated to respect different cultures and values and we must learn to see the line between research and morality. In this case, that line has been breached. Yanomami blood remains in a freezer at Penn State at the angst of an entire society, and for what purpose? Because of pride? Or fear? There may be no easy answer, but there is a resolution. Give back to the Toototobi Yanomami what belongs to them. Allow them to feel comfort in their relatives passing with peace in their hearts. End this controversy. Apathy will not dissipate the anguish the Yanomami feel; it will only propagate feelings of hurt and anger.

As President of Penn State University, it is your obligation to uphold the ethical standards of your university. I encourage you to show the world the importance you attach to such ethical standards and to right a wrong.

Sincerely,

Anne-Marie Rick (University of Notre Dame)

List of Additional Students Supporting Ms. Anne-Marie Rick's Letter to You:

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December 9, 2005

President Graham Spanier
Office of the President
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University Park, PA 16802

Dear Dr. Graham Spanier,

Science is a powerful tool. It can explain a remarkable variety of phenomena in the world around us, from the growth of plants, to the interactions of particles, to the dynamics of cultures around the globe.

However, science must be done in the right way. What does this entail? For all sciences, this means that evidence must be objective, verifiable, and reviewed by peers. Anthropology, however, has the unique characteristic that it deals with human subjects, rather than plants or protons or other unfeeling objects, so anthropologists must also be sensitive to the needs and desires of the people they study. Anything less and anthropology is simply destructive – both to the people being studied and to the discipline's claim to having principles and ethics. Anthropology's success as a science depends not only on it being rational and systematic, but also on its adherence to its moral code for performing study.

It is on these grounds that I would argue that the science being performed at your university on the Yanomami blood samples under the possession of Professor Kenneth M. Weiss is, in short, bad science. To save the face of anthropology as a science and as a discipline that is aware of and, moreover, responsive to the wishes of its human subjects, I urge you to immediately return the Yanomami blood samples. If you keep the blood samples against the wishes of many of the Yanomami people, then the public image of the field of anthropology could be damaged for a long time to come – damage that is far more outreaching than the possible good that can come out of studying the Yanomami blood samples more.

In other words, if you keep the blood samples, you might make a few strides in science and make some more discoveries, but likely nothing groundbreaking. (Scientists have, after all, been studying these samples for forty years now.) The tradeoff for studying the samples further, however, is that anthropology loses its place on the high pedestal of morality and loses valuable trust with people outside the discipline. This damage affects anthropologists around the world. For example, how willing will people be to be subjects of anthropological study if anthropologists are known to occasionally act against their wishes and violate their values and beliefs? How

willing will people be to accept anthropology as a reliable, principled discipline if they are indifferent to the wishes of their subjects? In my opinion, the damage of further study of the Yanomami blood samples far outweighs the possible benefits.

Return the samples, and you save the face of anthropology as a discipline. It is imperative that we restore the public's trust in anthropology's sensitivity to the needs and wishes of its human subjects. Only then will the study of human beings that is anthropology be able to continue into the 21st century.

Dr. Graham Spanier, I urge you to act with foresight and shrewdness of mind. I urge you to return the Yanomami blood samples.

Sincerely,

Charlie Brummitt (University of Wisconsin, Madison)

List of Students Supporting Mr. Charlie Brummitt's Letter to You:

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Lucas Kressel (University of Wisconsin, Madison)
Linnea Kubiak (University of Wisconsin, Madison)
Megan Kultgen (University of Wisconsin, Madison)
Jodi Kurtz (University of Wisconsin, Madison)
Kelsey Larson (University of Georgia)
Patrick Lawson (University of Georgia)
Chamutal Leff (University of Wisconsin, Madison)
Naomi Lindberg (University of Wisconsin, Madison)
Molly Lowndes (University of Wisconsin, Madison)
Danielle Luciano (Hawaii Pacific University)
Erica Lui (Hawaii Pacific University)
Mai Luttrell (Hawaii Pacific University)
Kaitlin Maguire (University of Georgia)
Claire Marcus (University of Wisconsin, Madison)
Hayden Augustus Markette (University of Georgia)
Amanda Markowski (University of Georgia)
Rachel Marsh (University of Wisconsin, Madison)
Elsie Martinez - Pierce College)
Carolina Marx (University of Wisconsin, Madison)
William Mathews (University of Georgia)
Sam McAnear (University of Georgia)
Quincy McCrary (Hawaii Pacific University)
Jim McGahee (University of Georgia)
Morgan McManus (University of Georgia)
Suzy Menard (University of Wisconsin, Madison)
Jesse Meserole (University of Wisconsin, Madison)
Jackie Messler (University of Wisconsin, Madison)
Lauren Monteen (University of Wisconsin, Madison)

Danielle Moore (University of Georgia)
Erin Moriarty (University of Georgia)
Starr Moss (University of Wisconsin, Madison)
Eric Mulkey (University of Georgia)
Drew Muller (University of Georgia)
Matthew Nelson (University of Georgia)
Calen Nimmer (University of Wisconsin, Madison)
Christi Rourke (University of Georgia)
Robin Oates (University of Georgia)
Corey Olson (University of Wisconsin, Madison)
Pearman Parker (University of Georgia)
Dimple Patel (University of Georgia)
Pranav Patel (University of Wisconsin, Madison)
Kevin Patterson (University of Georgia)
Lisa Paulos (University of Wisconsin, Madison)
Cory Peisel (University of Georgia)
Benjamin Perlow (University of Georgia)
Alan Piotrowicz (University of Wisconsin, Madison)
Justin Porter (University of Georgia)
Johnna Powell (University of Georgia)
Gina Radewan (University of Wisconsin, Madison)
Kristen Razner (University of Wisconsin, Madison)
John Reich (University of Wisconsin, Madison)
George Reichard (University of Georgia)
Mark Richter (University of Georgia)
Anne-Marie Rick (University of Notre Dame)
Adam Rogers (University of Georgia)
Ross Rortvedt (University of Wisconsin, Madison)
Martha Ross (University of Wisconsin, Madison)
Christopher Rutland (University of Georgia)
Evan Ryder (University of Wisconsin, Madison)
Emily Samuels (University of Georgia)
Joe Sarbacher (University of Wisconsin, Madison)
Kelly Schabel (University of Georgia)
Virginia Schickert (University of Wisconsin, Madison)
Rachel Schiesher (University of Wisconsin, Madison)
Gina Schmucker (University of Wisconsin, Madison)
Norman Scholz (University of Georgia)
John Schroeder (University of Wisconsin, Madison)
Ali Schultz (University of Wisconsin, Madison)
Emily Schwartz (University of Wisconsin, Madison)
Veronica Shapiro (University of Wisconsin, Madison)
Casey Shorts (University of Wisconsin, Madison)
Chris Slater (University of Georgia)
Jill Slaven (University of Wisconsin, Madison)

Spencer Smith (University of Georgia)
Lauren Steckler (University of Wisconsin, Madison)
Anne Marie Stoddard (University of Georgia)
Ben Stritesky (University of Wisconsin, Madison)
Megan Strohm (University of Wisconsin, Madison)
Kyle Taylor (University of Georgia)
James Teague (University of Georgia)
Pa Nhia Thao (University of Wisconsin, Madison)
Stephen Thurston (University of Georgia)
Jessica Tilghman (University of Wisconsin, Madison)
Tony Tran (University of Wisconsin, Madison)
Alicia Trevino-Murphy (University of Wisconsin, Madison)
Patrick Triggs (University of Georgia)
Leslie Trivett (University of Georgia)
Bryan Tublin (University of Wisconsin, Madison)
Stephanie Tudor (University of Wisconsin, Madison)
Nick Turner (University of Georgia)
Susan Un (Syracuse University)
Heather Van Duys (University of Georgia)
Eric Vandehaar (University of Wisconsin, Madison)
Leah Vanden Busch (University of Wisconsin, Madison)
Daniel VanDerWerff (University of Notre Dame)
Aixa Velez (University of Wisconsin, Madison)
Janet Villanos (Hawaii Pacific University)
Mariel Vinge (University of Wisconsin, Madison)
Shama Virani (University of Wisconsin, Madison)
Yee Vue (University of Wisconsin, Madison)
Jacob Wagner (University of Wisconsin, Madison)
Becka Walcott (University of Georgia)
Sarah Walorski (University of Notre Dame)
Jeffrey Ward (University of Georgia)
Aaron Wiegel (University of Wisconsin, Madison)
Cody Williams (University of Wisconsin, Madison)
Amanda Woodruff (University of Georgia)
Lauren Wright (University of Georgia)
Jessica Zarra (University of Notre Dame)
Lauren Ziskind (University of Wisconsin, Madison)
Jaime Zwiers (University of Wisconsin, Madison)