



Havasupai Tribe, Genetic Research, Informed Consent, and Culturally Sensitivity

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Image retrieved from <http://theofficialhavasupaitribe.com/About-Supai/about-supai.html>

Havasupai Tribe Havasu Baaja

- People of the Blue Green water
- Supai, AZ
- Hidden limestone aquifer
- 1882 Tribe's Grand Canyon land declared to be a national park
- 100 years later the Government restored 185,000 acres to the tribe
- Tribe Ravaged by type 2 Diabetes



Image retrieved from <http://theofficialhavasupaitrbe.com/About-Supai/about-supai.html>

Also known as the People of the Blue Green water.

The tribe lives in Supai, AZ, which is over 1,000 years old. It is a remote village that is located eight miles below the rim of the Grand Canyon. You must hike in to get to the village.

A hidden limestone aquifer provides the blue green waters that nourish fields of corn, squash and beans for the tribe in the harsh desert landscape which supported the tribes way of life.

In 1882, the US Government declared the tribe's Grand Canyon land to be a national park. The Havasupai were confined to a small area at the bottom of the canyon.

After a long 100 years, the US Government finally restored 185,000 acres back to the tribe.

By that time traditional hunting, fishing, and farming had already been replaced by tourism. Along with the tourists and visitors came new non-native food and drinks. The Havasupai were ravaged by type 2 diabetes.



A brief history of the Havasupai as told by a tribal member.
Retrieved from <https://www.youtube.com/watch?v=WcIkah78LMQ>

A History of American Indian Trauma, Ethnocide and Genocide

- AIs (American Indians) forcibly removed
- Native languages and religious practices were banned
- Courts of Indian Offenses 1882: “discouraged” “heathenish” AI cultural practices
- Late 1800s-early 1900s: AI children forcibly removed
- 1946-1964: “Termination”
- 1973–1976: 3,406 involuntary sterilizations

AIs (American Indians) were forcibly removed from their homelands by governmental authorities and resettled in areas unfamiliar to them.

Native languages and religious practices were banned.

In 1882, Courts of Indian Offenses “discouraged” “heathenish” AI cultural practices, including certain dances, rituals, and use of traditional healers.

In the Late 1800s to early 1900s, AI children were forcibly removed from their families and sent to federal Indian boarding schools that were designed explicitly to extinguish Indian cultures.

Between 1946 and 1964 there was a period of “Termination” where 109 tribes were terminated, approximately 2,500,000 acres of tribal land were removed, and 12,000 AIs lost tribal affiliation.

Between 1973 and 1976 there were 3,406 involuntary sterilizations performed on AI women age 15 to 44. They were told that they would lose their access to Bureau of Indian Affairs benefits, access to IHS health care, and possibly the custody of their children, if they did not allow the sterilizations.

Havasupai Diabetes Research: Asking for Help and a Trusting Relationship

- Devastating diabetes epidemic, 4th highest prevalence in the world, 45% of men and 50% of women
- 1989 Havasupai approached John Martin
- Martin approached Theresa Markow
- Markow expressed interest in schizophrenia research, her area of expertise
- Grant from the National Alliance for Research on Schizophrenia and Depression



Among the Havasupai diabetes became an epidemic. Havasupai had the 4th highest prevalence in the world, 45% of men and 50% of women.

In 1989 the Havasupai approached John Martin, an anthropologist at Arizona State University. Martin, who since 1963 had cultivated a strong relationship with tribe, offered to help with the diabetes epidemic in 3 ways:

- (1) provide education on nutrition and physiology
- (2) arrange for testing to determine which tribal members were diabetic or at risk
- (3) make genetic testing available to see if gene variants correlated to incidence

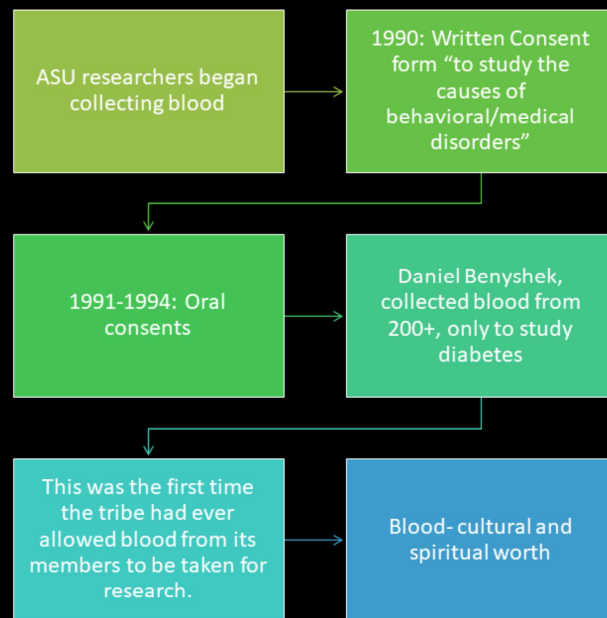
Martin then approached Theresa Markow, a zoologist and human genetics professor at ASU, about working on a “diabetes-centered project.”

Markow expressed her interest in expanding research to include schizophrenia, her area of expertise. Martin informed Markow that Havasupai tribal members would probably not be interested.

Markow applied for and received a grant from the National Alliance for Research on

Schizophrenia and Depression to study schizophrenia among Havasupai without tribal permission.

Havasupai Diabetes Research: Blood Collection and Informed Consent



After repeatedly stressing to the Havasupai Tribal Council that diabetes was the sole purpose behind the research, ASU researchers began collecting blood.

In 1990 blood collection began and had a written consent form stating that the purpose of the research was “to study the causes of behavioral/medical disorders.”

Between 1991 and 1994, oral consents were obtained prior to sample collecting.

A graduate research assistant, Daniel Benyshek, collected blood from 200+ tribal members and explained blood would be used only to study diabetes, as was his understanding.

This was the first time the tribe had ever allowed blood from its members to be taken for research, showing a big step in trust in the researchers and Martin.

Blood holds significant cultural and spiritual worth to the Havasupai.

Research Goes to Far: Violation of Trust

- Diabetes not only of genetic origin.
- November 1991: Article published by Markow on diabetes research
- 1990-1994: Markow did unauthorized additional research
- 1990: Markow instructed a data collector to look for indications of schizophrenia



Image retrieved from <http://theofficialhavasupaitrbe.com/About-Supai/about-supai.html>

Researchers concluded that the rate of diabetes was growing too quickly to be only of genetic origin.

In November 1991, an article was published by Markow that reported that there was “too little variation among tribal members’ genetics to conclude the incidence of disease among them was genetics-related.”

Between 1990 and 1994, Markow and ASU did additional research on tribal members’ blood without tribal consent.

It was later discovered that in 1990, Markow instructed a data collector to review medical charts in the IHS clinic on the Havasupai Reservation to look for indications of schizophrenia. This was done without the approval of ASU, its institutional review board, the IHS, the tribe, or participants.



2003: Martin invited Carletta Tilousi to a doctoral dissertation defense



After Tilousi questioned about permissions, the defense was quickly halted



Havasupai Tribal Council informed of mishandled tribal members' blood samples



On May 9, 2003, after not receiving information, the tribe issued a Banishment Order

Discovered Breach in Trust

In 2003, Martin invited Carletta Tilousi, a tribal member and ASU undergraduate student, to a doctoral dissertation defense, presented by Daniel Garrigan that focused on population migration theories related to the Havasupai blood samples.

Tilousi then questioned Garrigan as to whether he had obtained tribal permission to use the blood samples for his study. Garrigan admitted that he had not. The defense was quickly halted, and Garrigan was told to redact from his dissertation the chapter mentioning the Havasupai blood samples.

Martin informed the Havasupai Tribal Council that ASU had mishandled tribal members' blood samples, and the tribe requested further information from ASU.

On May 9, 2003, after not receiving information, the tribe issued a Banishment Order:

“The Havasupai Tribe has recently been informed by reliable sources that Havasupai blood collected by ASU has been distributed to others for research, and that research may have been conducted on Havasupai blood, by [ASU] and by others, for purposes unrelated to diabetes or any other medical disorder, all in violation of the consent given by Havasupai members.

** * *[ASU], its Professors and employees are, from this date forward banished from*

the Havasupai Reservation.

The Hart Report

- Stephen Hart commissioned to conduct an independent investigation
- No concrete findings of wrongdoing but some issues
- Found scientists used blood samples to study additional genetics without consent
- Academic papers, articles, and dissertations written



Image retrieved from <https://www.nps.gov/grca/planyourvisit/havasupai.htm>

Havasupai Tribe and the Arizona Board of Regents commissioned attorney Stephen Hart to conduct an independent investigation.

There were no concrete findings of wrongdoing, however, there were issues found with how the project was administered, the keeping of records, and whether the tribe realized the full extent of the research that would be undertaken.

Hart also found that scientists used the blood samples to study the genetic causes of schizophrenia, inbreeding, and population migration theories, both at ASU and other research institutions, without the tribe's consent.

Academic papers, articles, and dissertations were written that used or referenced the Havasupai blood as a source; most not related to diabetes.

Lawsuits



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- 2 lawsuits filed. *Tilousi v Arizona State University Board of Regents*, *Havasupai Tribe v Arizona State University Board of Regents*
- Cases tied up for nearly 6 years
- April 20, 2010 cases settle
- Settlement included:
 1. return the 151 remaining blood samples
 2. pay \$700 000 to 41 tribal members
 3. return all laboratory books and genealogy materials containing research derived from the blood samples
 4. mandate that the ASU institutional review board not approve ongoing or new research involving the samples
 5. provide the tribe with a list of who received the blood samples

There were 2 lawsuits that were filed. Tilousi and 51 tribal members filed *Tilousi v Arizona State University Board of Regents*; the Havasupai Tribe filed *Havasupai Tribe v Arizona State University Board of Regents*.

The cases were tied up in procedural motions for nearly 6 years.

Finally on April 20, 2010, Havasupai Tribe and the Arizona Board of Regents had settled.

The Settlement included:

1. return the 151 remaining blood samples,
2. pay \$700 000 to 41 tribal members,
3. return all laboratory books and genealogy materials containing research derived from the blood samples,
4. mandate that the ASU institutional review board not approve ongoing or new research involving the samples, and
5. provide the tribe with a list of who received the blood samples.

The settlement also created a 5-year agreement between the Arizona Board of Regents and the Havasupai Tribe to address the tribe's needs in such areas as education, health and nutrition, and economic development. The most importance

part of the settlement was the return of the blood samples. The blood collection began in 1990, and by the time of the settlement, 32 tribal members who donated blood had died. The Havasupai believe that when an individual dies, they cannot pass on to the next world unless they were buried with all of their possessions. “When you have blood samples being held in a laboratory, the transition to the next world is not completed. That’s why we needed these samples.”



One must consider the mistrust of the scientific community, due to repeated, well-documented unethical medical research, clinical misconduct in the name of research, and the history of general mistreatment.

We must remember the broken implied and legally binding agreements in cases over at least the last 100 years and the impact that has on the perspective of minority cultures.

There is a significant history of studies where researchers failed to obtain informed consent, modified protocols without consulting participants, withheld information, and failed to follow up as planned.

A study was done that showed the attitudes of ethnic minorities were that of fear and mistrust. These are huge deterrents to participation in research and their medical care trust.

Many minorities and AI's have an inability to distinguish between unethical instances that occur in the medical realm vs research realm; these acts are seen as deriving from the same people.

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