Havasupai Tribe v. the Arizona Board of Regents (2008)

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In 2004, the Havasupai Tribe filed a lawsuit against the Arizona Board of Regents and several Arizona State University professors after discovering that the scientists had used blood samples from members of the tribe for research on type 2 diabetes in unrelated genetic studies. The study participants were not aware the researchers were using their samples in the study of highly taboo topics in Havasupai culture, such as schizophrenia, ethnic migration, and population inbreeding. The Havasupai Tribe alleged that the collection of samples constituted a violation of informed consent, or an individual's agreement to participate after receiving an accurate and comprehensive explanation of the intended usage of their genetic material. The lawsuit, *Havasupai Tribe v. Arizona State University Board of Regents,* reached a settlement in April 2010 that included monetary compensation from Arizona State University and the return of the samples to the Havasupai community. Although the case did not set an official legal precedent, it sparked discourse regarding informed consent and ethical research practices when conducting genetic research with Native American communities and other vulnerable populations.

The Havasupai Tribe

The Havasupai Tribe is a Native American tribe located primarily in the Grand Canyon region of northern Arizona. The Havasupai's reservation consists of 188,077 acres of land beside the western edge of the Grand Canyon's South Rim. Their most concentrated urban settlement is the remote village of Supai, Arizona, which is situated eight miles below the rim of the Grand Canyon and is only accessible by foot, mule, or helicopter. The community has been living in Supai for over 1,000 years. There is a deep cultural belief among the Havasupai that the tribe originated in the canyon and has since been serving as its guardian.

As of 2025, the tribe consists of approximately 639 enrolled members. The main occupation of the inhabitants of Supai is working in the tribe-run tourism industry to facilitate tours to Havasu Falls, which is a large waterfall in Havasu Canyon directly adjacent to the Grand Canyon.

Historical Context

In 1963, John Martin, an anthropology professor at Arizona Statute University, or ASU, in Tempe, Arizona, began studying the Havasupai Tribe in Supai. Martin continued working with the tribe over the next several decades and collaborated with tribal leadership to organize community action and development programs, as well as conduct social and environmental studies. In 1989, a member of the tribe asked Martin to investigate the alarming rate of type 2 diabetes among tribal members. Researchers had already identified genetic links to diabetes in people with ancestry to the O'odham peoples, who inhabit central Arizona. Martin hypothesized that the prevalence of diabetes in the Supai community might be related to genetics and diet.

Martin approached Therese Markow, one of his colleagues at ASU and a researcher studying the genetic foundations of disease, to help organize a study examining the genetic factors associated with diabetes amongst the Havasupai Tribe. Markow had previously conducted research on other diseases, specifically schizophrenia. According to an opinion written by Diane Johnsen, a former judge on the Arizona Court of Appeals, Markow expressed a desire to include mental disorders in the study's analysis. Martin told Markow that it was unlikely that the Havasupai Tribe would be interested in that topic due to the stigma surrounding mental health in the community. Markow later claimed that Martin had actually lured her into joining the study by mentioning that there was allegedly a high incidence rate of schizophrenia in the Havasupai population and that he had traced the disease back to a single tribal ancestor, a shaman who had died in the early 1900s.

In the fall of 1989, Martin and Markow applied for funding from ASU for their diabetes-centered project. The project consisted of genetic collection and research, as well as an educational program for members of the tribe to take summer classes at ASU on nutrition and diabetes. ASU allocated $24,420 for the education program, thus allowing fifteen tribal members to attend summer classes, and $240,000 for three years of diabetes research.

Markow also independently applied for a research grant from the non-profit organization National Alliance for Research on Schizophrenia and Depression, or NARSAD, to study schizophrenia in Supai. In her grant, Markow claimed that Havasupai medical records revealed an incidence of schizophrenia seven times that of the general population. Schizophrenia experts and Indian Health Service officials told reporters from the *Phoenix New Times* in 2004 that there were no studies at that time investigating the prevalence of

schizophrenia in the Havasupai Tribe and that they were unsure of where Markow derived her statistics. In March 1990, Martin and Linda Vaughan, a professor of nutrition at ASU, delivered a formal pitch for the project at a meeting of the Tribal Council of the Havasupai, where they received permission to implement that project in the community. In May 1990, Markow received a $92,880 grant from NARSAD to study schizophrenia in the Havasupai, but neither she nor her collaborators informed the Tribal Council of that additional funding nor the additional topic.

In the summer of 1990, the researchers began collecting blood samples. In addition to written consent forms, they delivered an oral presentation using a script that Markow wrote. The script briefly mentioned schizophrenia but in a context that made it appear as an example of a genetically driven condition. The written consent form explained that the purpose of the research was to study the causes of behavioral/medical disorders. Between 1990 and 1992, more than 200 Havasupai individuals provided blood samples to the study. Martin and Markow recruited Kevin Zuerlein, a young psychiatry resident at Maricopa Medical Center in Phoenix, Arizona, to assist in blood collection. Under Markow's request, Zuerlein also reviewed Havasupai medical records for evidence of schizophrenia. They did not receive permission from the Tribal Council or inform any member of the Havasupai tribe. In 1991, Zuerlein, Martin, Markow, and Vaughan published a paper in the medical journal *The Lancet*, in which they assert that there is no significant evidence to suggest a genetic causation of the high prevalence of diabetes in the Havasupai community, but sample collection continued even after the publication of that finding.

In January 1991, ASU's Institutional Review Board, or IRB, a committee that oversees research involving human subjects to ensure compliance with ethical and legal regulations, approved Markow's proposal to study the genetic underpinnings of schizophrenia, which Markow titled "Schizophrenia: A Genetic Model" and intended to last three years. Markow continued to receive blood samples and conduct schizophrenia research throughout the early 1990s. When she relocated to the University of Arizona in Tucson, Arizona, in 1999, Markow took a portion of the Havasupai blood samples with her, despite promises to tribal leaders that their genetic material would remain at ASU. Markow also sent Havasupai blood samples to research collaborators around the United States, including scientists at Stanford University in Stanford, California, and employees at a for-profit pharmaceutical laboratory in California.

In March 2003, Carletta Tilousi, a member of the Havasupai Tribe and a student at ASU, was visiting Martin at his office when he invited her to the doctoral dissertation defense of Daniel Garrigan, one of Markow's graduate students. When the *Phoenix New Times* contacted her in 2004, Tilousi stated that Martin informed her that Garrigan's research involved the use of the Havasupai blood samples, which piqued her interest. In his dissertation defense, Garrigan presented population migration theories regarding the Havasupai tribe and explained that the

Havasupai had migrated from Asia to Arizona, a finding that contradicted the Havasupai's cultural belief that they originated in the Grand Canyon. During the question portion of the defense, Tilousi asked Garrigan whether he had obtained tribal permission to use the blood samples for his study. Garrigan admitted that he had personally not, but he had thought that Markow had obtained permission on his behalf. His doctoral committee quickly ended the defense and told Garrigan to remove the chapter mentioning the Havasupai blood samples from his dissertation. Shortly after the defense, Martin approached university officials and requested that they return the blood samples to the community to settle the dispute, but they did not acquiesce. He also informed the Havasupai Tribal Council that ASU had mishandled the blood samples. On 9 May 2003, the tribe issued a Banishment Order, stating that they were now aware that researchers had used Havasupai genetic material for studies unrelated to diabetes or any other health condition and that employees of the university were now banned from the Havasupai Reservation.

Legal Proceedings

Shortly after the Banishment Order, the Havasupai Tribe and the Arizona Board of Regents, or ABOR, commissioned Stephen Hart, a Phoenix attorney with experience working with Native American communities, to conduct an investigation into the informed consent procedures involved in the collection of the blood samples and their subsequent uses. Hart issued his final report on 23 December 2003, which consisted primarily of a collection of interviews. That report did not identify any conclusive findings of misconduct but found issues with the administration of the project, including record keeping and the researchers' failure to ensure that tribal leadership realized the full extent of the research. Hart also discovered that scientists used the blood samples to study a variety of subjects. Researchers had published twenty-three academic papers, articles, and dissertations using Havasupai blood samples as primary source material, but fifteen of those works were unrelated to diabetes. The tribal members primarily objected to studies centered around schizophrenia, inbreeding, and evolutionary genetics suggesting that the ancestors of the Havasupai Tribe migrated from Asia. In February 2004, Tilousi and fifty-one other tribal members filed *Tilousi v. Arizona State University* (2004), and on 12 March 2004, Havasupai Tribe filed *Havasupai Tribe v. the Arizona Board of Regents* (2008). Both claims alleged that the actions of the ASU researchers constituted wrongdoing and ultimately resulted in harm to the Havasupai community.

In *Tilousi v. Arizona State University Board of Regents*, Tilousi and other members of the tribe alleged that there was a breach of fiduciary duty, or the duty to act ethically, and a lack of informed consent. They also alleged that there was fraud, misrepresentation, fraudulent concealment, intentional and negligent infliction of emotional distress, violation of civil rights, negligence, an unreasonable disclosure of private facts, intentional intrusion upon seclusion,

and conversion, which is the unlawful act of taking property without permission. The Arizona District Court dismissed many of those claims, stating that Tilousi and the other Havasupai plaintiffs had failed to assert damages and other essential elements of individual claims.

Concurrently with Tilousi's individual lawsuit, the Havasupai tribe filed *Havasupai Tribe v. Arizona State University Board of Regents*, alleging state and federal claims against the ABOR and Markow. Prior to that, they had filed three separate notice-of-claim letters on 8 September 2003, 5 March 2004, and 31 March 2004. The notice-of-claim letter they filed on 5 March 2004 states that the Havasupai tribe would settle the claims for fifty million dollars. In their letters, the Havasupai tribe also established that, under the doctrine of *parens patriae*, which is the legal ability of a state to bring a lawsuit on behalf of a citizen, they were representing all tribal members who were involved in the diabetes project. ABOR and Markow removed, or transferred, the complaint to federal court, which dismissed the claims of a violation of federal law and the *parens patriae* claims. The court gave the Havasupai tribe permission to allege claims for the breach of fiduciary duty, fraud, negligence, and trespass.

The federal court remanded the case, or sent the case back to the state court, and the Havasupai tribe filed an amended complaint in the Arizona Superior Court. ABOR filed a summary judgment, which is a legal procedure in which one party asks the court to decide the case in their favor without a full trial. They claimed that the Havasupai tribe had failed to comply with Ariz. Rev. Stat. § 12-821.01. That specific section of the Arizona Revised Statutes states that people must file claims against a public entity within 180 days after the offending incident and must include a specific amount for which the claim can be settled, as well as factual evidence supporting that amount. ABOR and Markow argued that the Havasupai Tribe's September 2003 notice-of-claim did not identify a specific amount and that the tribe had sent the other notice-of-claims past the 180-day deadline. The superior court approved the summary judgment and stated that there was inadequate explanation in the notice-of-claim letters as to why fifty million dollars was an appropriate amount of money to settle the claim.

Despite the dismissals, Tilousi and the Havasupai tribe joined their claims and appealed the decisions in the Arizona Court of Appeals. On 20 April 2009, the court reached a decision, in which they reversed the Arizona Superior Court's summary judgment orders and sent the case to lower courts for further action. They concluded that the Arizona Superior Court erred in granting summary judgment against the Havasupai Tribe, and their reasoning relied primarily on the precedent set by *Backus v. State* (2009), a case in which Michael Backus filed a lawsuit against the State of Arizona after sustaining injuries in an accident that occurred while he was a passenger on a state-operated bus. Backus claimed that the state was negligent in maintaining the bus and the roadway. *Backus v. State* had asserted the proposition that a notice-of-claim letter is sufficient if it contains any facts at all.

The Arizona Court of Appeals held that the letters had included several details describing the alleged wrongdoing by ABOR and Markow, thus finding that the evidence presented in the Havasupai tribe's notice-of-claim letters adhered to Ariz. Rev. Stat. § 12-821.01. The case continued to undergo litigation until the Havasupai tribe and ABOR arrived at a settlement agreement in April 2010 after seven years of legal arguments. ASU agreed to pay $700,000 to 41 tribal members and return the blood samples. ASU also promised to provide other services to the Havasupai tribe, such as scholarships for tribal members to attend the university and assistance in funding a new health clinic in Supai. In April 2010, Tilousi and a delegation of tribal members removed the blood samples from ASU's campus in Tempe while they cried and sang in Havasupai.

In a letter to *The New York Times* published in May 2010, Markow asserts that ASU's decision to settle the case does not constitute an admission of guilt or a condemnation of the researchers. She states that she believes that media coverage of the dispute, specifically in reference to an article published by *The New York Times*, did not provide full context and increased the mistrust between underserved populations and researchers. According to a 2008 article in *Arizona Daily Sun*, Markow states that the claims of the Havasupai community were hysterical and that she was only doing good science. As of 2025, Markow is Professor Emeritus at the University of California, San Diego in San Diego, California, and leads a group researching the genetics of fruit flies.

Impacts

Although *Havasupai Tribe v. Arizona State University Board of Regents* did not set a formal legal precedent due to the lack of a decision, the case affected the attitudes of many Native American tribes towards participation in medical studies. According to Havasupai culture, blood is not merely an item of scientific value, it is an important part of an individual's identity and retains a separate identity when it leaves the body. By the time the parties settled the case, thirty-two of the tribal members who had donated blood had died, and, according to Havasupai culture, they were unable to pass onto the next world until their community was able to properly bury their blood. According to reporter Amy Harmon in an article for *The New York Times*, ASU's research on schizophrenia, inbreeding, and population migration theories also deeply offended the tribe. Many members have avoided seeking medical care due to their mistrust of the scientific field.

Due to *Havasupai Tribe v. Arizona State University Board of Regents* and prior instances of genetic research injustices, many tribes refused participation in genetic studies despite researchers' interest in involving them in research that may provide them with healthcare benefits. According to Rebecca Tsosie, a professor of law at the University of Arizona whose work centers on the cultural rights of Native American tribes, there are several potential

harms that arise from genetic research. Examples include the failure of scientists to recognize and honor the meaning of biological materials, worry from the community that researchers will use samples for unauthorized purposes, and fear from participants that the information derived from the samples will breach the privacy of their originators.

According to LorrieAnn Santos, the co-director of the Native Hawaiian Cancer Network, Native American communities and the scientists who work with them have widely adopted principles of community-based participatory research, or CBPR. CBPR has existed as a branch of action research, a research method with an emphasis on problem-solving and stakeholder participation, since the 1940s. Social scientist Kurt Lewin developed that method as a means to use research for planned social change. CBPR requires that biomedical research address the health of the community within broader cultural, social, economic, and political contexts, as well as involve the community at all levels, identify community needs and concerns, build on the strengths and resources within the community, promote co-learning and knowledge transfer, and provide tangible benefits to the community. *Havasupai Tribe v. Arizona State University Board of Regents* reiterates the importance of research approaches that consider the needs and culture of its target population.

Although *Havasupai Tribe v. Arizona State University Board of Regents* did not reach a formal decision or set official legal precedent, it emphasizes the necessity for researchers to understand the perspectives and values of their populations of interest and consider that information when developing studies. The lawsuit serves, according to some perspectives, as an example of a violation of informed consent and an instance in which researchers failed to fulfill the collective interests of a vulnerable community. The case highlights considerations regarding future research studies, especially among Native American populations. It suggests the need for the development of partnerships between academic institutions and the communities that they study.

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