

RESOLUTION OF THE
WHITE MOUNTAIN APACHE TRIBE OF THE
FORT APACHE INDIAN RESERVATION

- WHEREAS, the Tribal Council on June 7, 1995, reviewed and approved a proposal presented by the Indian Health Service (IHS) to close the medical study, "Diabetes in White Mountain Apache Mothers and Infants," conducted by Principal Investigator, Dorothy Hollingsworth, M.D., of the University of California at San Diego, School of Medicine (UCSD); and
- WHEREAS, this study was conducted on the Fort Apache Indian Reservation under the sponsorship of UCSD, IHS and the National Institutes of Health (NIH); and
- WHEREAS, it was found that the Principal Investigator obtained some research blood samples from study participants without first obtaining their informed consent; and
- WHEREAS, the Principal Investigator had obtained blood samples and chart information from some participants even though those women had refused to participate in the medical study; and
- WHEREAS, following the disclosure of these serious improprieties the Principal Investigator did not comply with the lawful temporary suspension of the research project, effective December 9 1994, as ordered by the IHS and UCSD Institutional Review Boards (IRBs); and
- WHEREAS, it is documented that after the suspension order, the Principal Investigator, on January 20 1995, unilaterally and without authorization destroyed a large number of blood samples taken from White Mountain Apache Tribal women, the action being a clear violation of the lawful temporary suspension of the research project; and
- WHEREAS, it is also documented that after the suspension order, the Principal Investigator obtained personal access to study participants through the delivery of a letter which raised inflammatory and misleading accusations about IHS personnel; and
- WHEREAS, it is reported that the Principal Investigator made repeated attempts to publish and disseminate data obtained from the study without seeking permission from the Tribe; and

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- WHEREAS, by her actions the Principal Medical Investigator abused the privacy of the people of the White Mountain Apache Tribe, in her drive to satisfy her professional goals; and
- WHEREAS, the Principal Medical Investigator may have harmed the trust Tribal members have for the providers of medical care on the Reservation; and
- WHEREAS, the Principal Medical Investigator's retaliatory destruction of data and samples undermined the good faith efforts of those Tribal members who voluntarily participated in the study; and
- WHEREAS, these actions add to an unfortunate pattern established in some previous studies which have degraded Tribal values and integrity in the pursuit of expanded scientific knowledge; and
- WHEREAS, the Tribal Council concludes that the Principal Investigator's conduct warrants investigation for possible criminal prosecution for her deeds and conduct on the Fort Apache Indian Reservation, as described herein; and
- WHEREAS, the Tribal Council has on this date received and reviewed the final report from the IHS concerning the project closure; and
- WHEREAS, the project closure process, paid by the NIH, directed by UCSD, and with the on-site supervision of the Whiteriver Service Unit (WRSU), after intense and prolonged efforts was able to contact 125 women (54%) of the 230 women known to have had substantial participation in the research project; and
- WHEREAS, the project closure process found that some women expressed concerns about the possibility of becoming involved in research in the future; and
- WHEREAS, scientists at UCSD examined the database and remaining blood specimens for possible scientific value if the study were completed as originally planned; and
- WHEREAS, the UCSD scientists found that due to the Principal Investigator's destruction of blood samples on January 20 1995, and due to the small number of women whose blood was still saved and frozen for testing who were able to be contacted for re-consent, there is no scientific value in continuing the study because the remaining sample size is too small to give scientifically valuable information; and
- WHEREAS, the various Institutes of the NIH, and the various Centers of the Centers for Disease Control and Prevention (CDC), are major funders of grants, contracts, and cooperative agreements for research in American Indian and Alaska Native reservations; and

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WHEREAS, the IRBs and Offices of Grants in the NIH and CDC are not sufficiently familiar with the requirements for official tribal government review and approval of research done within Indian reservations, and of all publications derived from that research; and

WHEREAS, the Indian Health Service has not yet met with the IRBs and Offices of Grants in the NIH and CDC to inform them about the requirements for review and approval by Tribal governments, waiting until the White Mountain Apache Tribal Council resolved this issue.

BE IT RESOLVED by the Tribal Council of the White Mountain Apache Tribe that the research project "Diabetes in White Mountain Apache Mothers and Infants" is permanently halted and stopped.

BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that the blood samples (many of which were obtained without prior informed consent being given by the women) that were not destroyed by the Principal Investigator should be disposed of in a respectful manner.

BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that the data (much of which were obtained without prior informed consent being given by the women) that were not destroyed by the Principal Investigator should also be disposed of.

BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that UCSD should keep the data and information about the project closure under complete security to prevent mis-use, and should keep the data and information only through the period required by Federal and California regulations covering grants and research, and then should dispose of the data and information.

BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that no publication should be derived from, or be about, the research project "Diabetes in White Mountain Apache Mothers and Infants."

BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that no publication should be derived from, or be about, the closure process.

BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that the project closure personnel, UCSD, WRSU, and the project closure advisory group are thanked for their efforts.

BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that hereafter all medical investigators for every research project must receive prior approval by the Tribal Council and must agree in writing to (1) abide by the laws and regulations of the White Mountain Apache Tribe, including the strict procedures governing the dissemination or publication of any data or information derived from or about the research, (2) abide by the rulings of all IRBs, and (3) agree to be bound by a liquidated damages provision for the breach of any of the foregoing conditions.

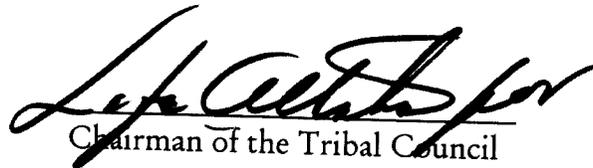
BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that in the future it intends to seek criminal prosecution under applicable criminal laws for similar conduct by any investigator for any research project on the Fort Apache Indian Reservation.

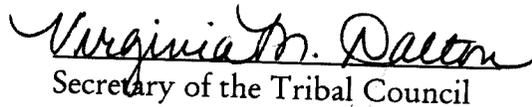
BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that IHS should meet with the IRBs and Offices of Grants in the NIH and CDC, to explain to them about the general requirement for review and approval by tribal governments of research and resulting publications, and about the policy of the White Mountain Apache Tribe in particular.

BE IT FURTHER RESOLVED by the Tribal Council of the White Mountain Apache Tribe that IHS should report to the White Mountain Apache Tribal Council when that activity has been accomplished.

The foregoing resolution was on April 11, 1996, duly adopted by a vote of ten for and zero against by the Tribal Council of the White Mountain Apache Tribe, pursuant to authority vested in it by the White Mountain Apache Tribal Constitution, including Article IV, Sections 1(a), (b), (q), (s), (t) and (u) of the Constitution of the Tribe, ratified by the Tribe on September 30, 1993, and approved by the Secretary of the Interior on November 12, 1993, pursuant to Section 16 of the Act of June 18, 1934 (48 Stat. 984).

APR 20 1996


Chairman of the Tribal Council


Secretary of the Tribal Council