



Strong Heart Study Newsletter

Investigating Cardiovascular Disease in American Indians

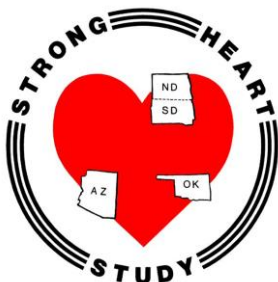
Updates for Community Members and Strong Heart Study Participants

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THE STRONG HEART STUDY AT 30 YEARS



**Celebrating 30 Years
of Successful
Partnership Between
Strong Heart Study
and
American Indian Tribes
in Southwest Oklahoma,
Arizona, North & South
Dakotas
To Improve Heart Health
of American Indians**



www.strongheartstudy.org

*SHS Shield by M. Red Bear, Lakota
Banner by Tauqeer Ali, MBBS, PhD*

The Strong Heart Study (SHS) began in 1988 to study cardiovascular diseases (CVD) and their risk factors among American Indian tribal groups residing in North and South Dakota, southwest Oklahoma, and Arizona. It has been continuously funded by grants from the National Heart, Lung, and Blood Institute (NHLBI). A population based sample of 4,549 tribal members ages 45-74 years made up the original cohort.

The initial objectives were:

- 1) To measure rates of CVD.
- 2) Measure CVD risk factors.
- 3) Determine the role of diabetes in CVD.
- 4) Follow participants to study trends in CVD and its risk factors.
- 5) Follow the group for all causes of mortality.

SHS PHASE 1 (1988 – 1991)

The initial baseline exam conducted in 1990-91 included a review of the medical history and current medications; a physical exam that included body measures, blood pressure, an electrocardiogram; and a questionnaire focused on diet and other lifestyle factors. Blood, urine and DNA samples were obtained for measures of CVD risk factors and samples were stored for further study. Medical records were reviewed for all causes of mortality and for non-fatal CVD events. Participants were contacted annually to see if any had experienced CVD events.

SHS PHASE 2 (1991 – 1996)

During a second exam of all surviving cohort members (90% participation) all of the basic measures were repeated with the addition of echograms (ultrasounds) of the heart and lung function testing to detect emphysema and/or asthma. Participants were contacted annually to determine CVD status and clinical records continued to be surveyed for causes of death and details of CVD events.

SHS PHASE 3 (1996 – 2000)

In addition to continued surveillance and review of clinical records, a third exam was conducted on all surviving cohort members (90% participation). Additional tests included carotid ultrasound to evaluate atherosclerotic plaques in the neck arteries; a measure of pressure waves velocity through the arteries; a measurement of carbon monoxide in exhaled air; and a pilot program to studying family groups.

SHS PHASE 4 (2000 – 2005)

The Strong Heart Family Study (SHFS) was initiated. The SHFS consisted of 3,838 participants, ages 15 years and older from 94 large families. An exam contained tests similar to those in the original cohort.

The SHFS permitted searches for genes possibly affecting CVD, diabetes and their respective risk factors. The other addition was the Stop Atherosclerosis in Native Diabetics Study (SANDS), a clinical trial in 500 participants from the 3 SHS centers and from a tribe in Northern AZ, which examined whether stricter control of blood pressure and cholesterol in individuals with diabetes would help prevent CVD. The results showed there was improvement in atherosclerosis and the functioning of the heart, and this and the data from SHS formed the basis for revised Indian Health Service guidelines for prevention of CVD in persons with diabetes.

SHS PHASE 5 (2005-2013)

We continued to follow the original cohort for CVD events and all causes of death. We also conducted a re-examination of the family group that contained all of the tests of the Phase 4 exam. Another ancillary study, the Strong Heart Stroke Study (SHSS) was instituted among all surviving members of the original cohort. It utilized brain scanning to see when certain changes in the brain could represent a “silent” stroke, an unstudied condition among Indian people, and to evaluate risk factors for stroke in the population.

SHS PHASE 6 (2013 - 2019)

We continued to follow the original cohort and the family members to determine CVD and other causes of death, and to track all nonfatal CVD events. Several studies were added during Phase 6. The Family Intervention in the Spirit of Motivational Interviewing (FITSMI) study had a goal to see if taking part in an interview, delivered in the format of a talking circle that focused on stroke and its risk factors, can help people live healthier lives with reduced risk of having a stroke. The second study focused on fatty liver disease and risk factors in a subset of the SHS participants. Investigators took MRI images that measure the amount of fat and scarring in the liver. These pictures tell us how much liver disease is in American Indians and helps to find ways to address it. Another ancillary study, called Rhythm and Timing, aims to improve mental functioning for American Indian elders who suffer from the effects of stroke and related diseases using drumming and songs from American Indian Communities. Almost no information is available on Alzheimer’s disease in American Indians. A fourth study will re-examine participants from the Strong Heart Stroke Study to see how common Alzheimer’s disease is and to find things that may protect against or lead to Alzheimer’s disease. In another study, called iDASH, researchers are building a new computing system to keep SHS data safe during analysis. The project includes discussions with tribal and community health leaders, and SHS participants, to learn about tribal group members’ preferences for the privacy and use of health data for research.

SHS PHASE 7 (2019 - 2026)

We will continue to follow the original cohort and the family members to determine CVD and other causes of death, and to track all nonfatal CVD events. New studies in areas of greatest interest to tribal communities, such as stroke, cognitive impairment, cancer, resilience, kidney function, food security and sufficiency, diabetes prevention in adolescents, atrial fibrillation and other heart problems, and oral health will be developed based on needs of the tribal communities.

SHS showed that CVD is a significant, and highly prevalent problem for American Indian communities. Participants were informed of abnormal results and SHS staff facilitated their referral for appropriate care.

SHARING YOUR STORIES

The SHS aims to improve the cardiovascular health of American Indian people. Here are some stories that you shared with us about the impact of the SHS on you, your family and your tribe and community.

My name is Thomas A. Holder Sr. I am 80 years old. I am enrolled with the *Delaware Nation of Oklahoma*. I started participating in the Strong Heart Study about thirty years ago. Strong Heart Study gives you the psychological and mental idea of the need for good health practices among the tribal people. Strong Heart Study was something that we needed in more ways than one. First of all we need to be more aware of the need to take care of ourselves personally, we need to attend to our own ways. But, we also have an obligation to our tribal people to help them to do things that they need to do. Strong Heart Study institutes new thoughts and new feelings about what you should be doing and what you shouldn't be doing to take care of your health.



SHARING YOUR STORIES (CONT.)



My name is Raquel Wildes and I am an enrolled member of the *Apache Tribe of Oklahoma*. I have been participating in Strong Heart for a long time, about 19 years. The reason I stayed with the study for this long is because it saved my life. My mom and grandma participated in this study. My mom had said that the Strong Heart Study invited me to participate in the family participation part of this study. I went to my Strong Heart Study appointment and they did an ultrasound of my heart (echocardiogram) and found a problem with my heart. They got on the ball immediately and notified my doctor and got me going, sent me straight on to Oklahoma City where I underwent a heart surgery immediately. I thank Strong Heart for being able to save my life. Because if it wasn't for that I probably wouldn't have been around. Anytime Strong Heart Study invites me to participate, I am open to

participate because I want to know what is going on with my health. Strong Heart Study benefits the community by them being able to find out what is going on in their body and with their health. I would let my children participate if or when they are able to. I think knowing that they could save your life by studies they are doing is very beneficial. With Strong Heart Study, you mostly think it is about the heart but they also check for other things like diabetes and your liver or kidneys. It is a participation in something that could save your life. If other people are offered the opportunity to participate, they should participate – it could be very beneficial to them.



My name is Eleanor Williams. I am an enrolled member of the Tohono O'odham Nation. I am from the village of Chu-Chu on the northern part of the Tohono O'odham reservation. It is the first village after you pass the cattle guard. I have enjoyed my years participating in the Strong Heart studies. I believe the first time I participated was in the early 90's. (*Phase 1; 1991*) I was interested in participating with the Strong Heart Study because I always learned so much. The first time I participated was in a little trailer. Everyone was so nice. I gained a lot of information about me, and my health. I also learned about other studies and the research happening to help our people. I remember one of the studies I really wanted to participate in but couldn't because it was



for people who had diabetes and I didn't have it. If you ask me, I think the reason for our health problems and diabetes are from the way we eat now; (fast food and a lot of sugar). We never used to eat like that. Things sure have changed. We used to eat from our fresh fruit trees we grew and our own gardens where we grew our own veggies. I was so happy to attend the community gathering. I especially enjoyed the delicious native foods. You don't see that too much anymore. It was so nice how you all put that event on just for us. I would attend another. I would like to see another one happen every year or at least every other year; with native foods of course, maybe entertainment like a chicken scratch band or a round dance group or other traditional dancing groups. I would really like to hear from other Strong Heart participants; their stories and experiences so we can help each other - that's education. I am grateful I was also connected with the Banner Alzheimer's Institute. It was the Strong Heart Study that connected me with them. I participated and will continue to participate with both of you. One last thing, I enjoyed participating in the exercise study for elders (Rhythm and Timing) I have two friends I want to refer to you who are interested in participating. ~ Thank you



30-YEAR CELEBRATIONS!

30-year celebrations have been held in Oklahoma, North and South Dakota and Arizona. We are happy to share a summary of these celebrations with you.

Arizona

Sheron and Agatha Manuel from the Salt River Pima Maricopa Indian Community

Our names are Sheron and Agatha Manuel, we come from here in the Salt River community. We have both participated in Strong Heart studies since the 90's (Phase 1, 1990) and have participated in other studies, including the Stroke Study.

Did you attend the community gathering the Strong Heart Study hosted?

Agatha: Sheron attended the Strong Heart community event. I wasn't able to go because I had dialysis that day and don't get out as much anymore. But I heard the event was very nice.

Sheron: Yes, I went to both events. It was very nice. I was a little disappointed because not everyone was there. It would be nice to have all the participants attend. I also think it would be nice to hear from the participants like the oldest one attending, or the person who has participated the longest. It was really nice to meet all of you also.

Would you attend another Strong Heart community event and how often should we have them? Do you have any suggestions for our next event?

Agatha: Yes, I would go. I think once a year would be good. I would like to see a chicken scratch band, even though I don't dance anymore I really like the music. Everyone does.

Sheron: Yes, we would. I think once a year would be nice. Maybe have it at the Multi-purpose building here in Salt River so everyone knows where it's at and its close by; then everyone would come. I think if you guys had a speaker also to share their experiences that would be good.

North and South Dakotas The Dakota Center staff have been excited to visit communities, and are always excited to visit with everyone about Strong Heart Study programs and results. Pilamayaye!



Pictures from the Lakota Invitational Tournament Booth in Rapid City on December 19 and 20, 2019. Staff talked to 500+ people each day about SHS results and ancillary studies.

30-YEAR CELEBRATIONS! (CONT.)

MBIRI went on the Radio Station at each of the 3 sites in the Dakotas to talk about SHS and 30th Anniversary. Pictured is the group at the Spirit Lake Radio KABU 90.7. Other radio sites visited include Oglala Lakota Radio Station, KILI at 90.1 and Cheyenne River Radio Station, KIPI at 93.5. MBIRI also worked with local persons to create a video titled *Impact & Importance of SHS*: <https://www.youtube.com/watch?v=W9gNAnyPxIA>



Spirit Lake Radio, KABU 90.7.



Staff at I.H.S. lobby (left) and local grocery store (right) sharing the good news about SHS and 30th Anniversary. Additional health fairs and school events were attended at Spirit Lake, Cheyenne River, and Oglala Lakota sites.



Provider Lunch & Learn (left) - Lyle Best, M.D. shared SHS information with I.H.S. and Tribal Health medical providers.



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30-YEAR CELEBRATIONS! (CONT.)

Oklahoma: The *American Indian Exposition* was held in Anadarko on August 14-17, 2019. It is a huge annual event that generally attracts 25,000 people. The Oklahoma Field Center SHS team set up a booth at this event where they performed free blood pressure and body mass index screening. They also handed out flyers and brochures with information about the SHS and health topics. This year was special – they set up the SHS 30th anniversary banner! One SHS participant came to the booth along with his spouse and said “I started participating in the SHS when it started 30 years ago”. He also stated that “SHS is very important for the community and it has benefited many people”. Other



SHS Team (left to right): Dr. Tauqeer Ali, Ms. Raekel Burrus, Ms. Halana Jay, Dr. Ying Zhang



SHS team members: Ms. Jessica Pohawpatchoko (left) and Ms. Shannon Mowatt (right)

participants who stopped at the booth said similar things and congratulated the SHS team.

We were also at the *Comanche Nation Fair* in Lawton (September 20-22, 2019), the *Health Fair at the Apache Tribe AOA Building* in Anadarko (September 27, 2019) and at the *Kiowa Complex Red Buffalo Hall* in Carnegie. Special mention about the SHS 30th anniversary was made at the SHS community meetings where the SHS investigators thanked the study participants, Tribal leaders, Southwest Oklahoma Intertribal Health Board, Indian Health Service Lawton Service Unit, and the Indian Health Service Oklahoma City Area Institutional Review Board for their continued support for the SHS. This 30 years of successful partnership is a group effort to improve health of American Indians. The findings from the SHS research show that it is generating positive results.