



STRONG HEART STUDY

INVESTIGATING CARDIOVASCULAR DISEASE
IN AMERICAN INDIANS

newsletter

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Strong Heart Study Oklahoma Hosts Community Meeting in Anadarko

The Oklahoma Center of the Strong Heart Study (SHS) hosted a community meeting on June 8th, 2007, in Anadarko, OK, to report some of the findings from the Strong Heart Study. More than 60 people attended the meeting. The investigators who presented included Thomas Welty, MD, (Dakota Center), Lyle Best, MD, (Dakota Center), Marie Russell, MD, (Arizona Center), Wm. James Howard, MD (Arizona Center and Washington DC), and Richard Fabsitz, Ph.D. (SHS NHLBI Project Officer). Prior to the presentations of SHS findings, Elisa Lee, Ph.D., (Oklahoma Center), offered the welcome to the guests and speakers in attendance. Linda Poolaw, long-time SHS employee and Anadarko resident, offered the introduction for the Invocation speaker, Dorothy Whitehorse DeLaune, Kiowa elder and noted traditional singer, storyteller, writer and historian. The luncheon speaker was Towana Spivey, the curator from the Fort Sill Museum.



Above: SHS PIs visit with community members before meeting.



Above: SHS employee Linda Poolaw.



Above: Invocation speaker Dorothy Whitehorse DeLaune.

Dr. Welty began the morning with his presentation, *How to Protect Your Heart and Blood Vessels*. Dr. Welty discussed the importance of cardiovascular disease prevention in SHS populations. He praised current research in Native communities but pointed out the need to accelerate practical prevention efforts and to obtain more financial support for clinical interventions. He recommended continuing research in intervention methods and ongoing surveillance of obesity, diabetes and cardiovascular disease to assess the impact of prevention. He also emphasized the importance of implementing prevention methods in public places including focusing on the youth, producing safe environments for exercise, smoke-free facilities and the necessity for tribal/community leaders to be role models in these prevention efforts. In addition, Dr. Welty emphasized that individuals and communities must overcome fatalism and understand that diabetes and cardiovascular disease can be prevented.

In Dr. Russell's presentation, *Metabolic Syndrome – What is it and Why Care*, she emphasized the importance of eating healthfully and exercising regularly to prevent metabolic syndrome (a set of specific risk factors such as large waist size and high blood pressure). In the SHS population, the metabolic syndrome was an indicator of future cardiovascular problems. Dr. Russell's prevention recommendations included eating fewer calories, less saturated fat, more whole grains, more fruits and vegetables, including fish in the diet and choosing healthier oils like olive oil or canola oil. She also recommended regular exercise, which improves all elements comprising metabolic syndrome. She recommended that everyone should perform some sort of moderate-intensity physical activity for 30-60 minutes at least 5 days a week.

Dr. Howard presented *Your Cholesterol and You: Lessons from Strong Heart* during which he reported that the SHS has found most heart attacks and strokes in SHS communities occur in those with diabetes, that LDL cholesterol is a strong predictor even though levels are generally low in American Indians, and that blood pressure is a strong predictor that leads to kidney disease, which also causes heart attacks and strokes. Based on these findings, Dr. Howard offered advice on how to avoid developing cardiovascular disease, e.g., by stopping smoking and developing healthy eating and exercise habits.

Dr. Best discussed *Genetics and Strong Heart Study*. Phase V of the SHS, which is now underway, has a strong focus on the role of genetics in cardiovascular disease in SHS communities. Dr. Best described the difficulties in pinpointing the role genetics play in diseases, but he also described the potential benefits of finding genetic ties to cardiovascular disease. Sometimes learning the role of genetics in a disease helps a great deal, enabling physicians and researchers to find

SHS OK Hosts Community Meeting

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ways to prevent or treat the disease. Often, genetics can help determine susceptibility to different diseases, the likely risk factors for a disease and which clues to pursue in trying to find treatments and to develop prevention strategies.

Dr. Fabsitz from the National Heart, Lung, and Blood Institute concluded the SHS presentations with a discussion of issues involved in sharing data collected in studies of AI/AN, such as Strong Heart. He discussed the advantages of data sharing, as well as the concerns. Dr. Fabsitz also reiterated the current SHS policy on data sharing, which is that data are only shared with investigators approved by Steering Committee based on scientifically sound proposals of high relevance to the goals of SHS. According to the strong belief that the benefits to be derived from SHS will be maximized if data and blood samples are shared with other reputable and respected investigators around the world, SHS resources are shared nationally and internationally as opportunities



Above: Luncheon speaker, Towana Spivey.

arise and approvals are given.

The audience at the community meeting also heard from a dedicated SANDS participant, Mr. Napoleon Tiddark, when he gave his heartfelt testimony about the positive experience he had with SANDS over the years. Many of the investigators, doctors, nurses, and staff from SHS are affiliated with SANDS (see the article below about SANDS ECHO), and Mr. Tiddark expressed his appreciation for everything the study has done for him and his health.



Above: SANDS participant Napoleon Tiddark.

The community meeting ended with a lunch and presentation from Curator Spivey called *Indians in the Military, with emphasis on the nineteenth century*. Mr. Spivey entertained the audience with details about tribal affiliations with the military in the southwest region of Oklahoma. He also gave insight into how the military in the area changed many ways of life for the tribes that included aspects of daily living like food and diet. Both food and diet play a large role in prevention of cardiovascular disease today.

SHS

SANDS Study Extension to Assess Cardiovascular Hard Outcomes

The Strong Heart Study brought to light the seriousness of hardening of the arteries (atherosclerosis) among Indians, particularly those with diabetes, and the Stop Atherosclerosis in Native Diabetics Study (SANDS) was developed by SHS investigators to find the best way to treat the problem. To include even more American Indians, the Navajo tribe was added to SANDS, a 5-year clinical trial that just ended in August 2007. The investigators are now applying to the National Heart, Lung, and Blood Institute (NHLBI) for funds to extend the study (Stop Atherosclerosis in Native Diabetics Study Extension to Assess Cardiovascular Hard Outcomes, SANDS ECHO).

The goal of SANDS was to see if treating blood pressure and cholesterol to targets that are lower than the usual clinical goals would help to prevent diseases of the heart and blood vessels. To do this, SANDS used what are known as "surrogate endpoints" to see whether the treatments helped prevent CVD. These surrogate endpoints (ultrasound measurements of the heart and of the main arteries in the neck) are a substitute for "hard endpoints" (for example, heart attacks and strokes) that usually take several years to develop. Many studies use these surrogates because we would otherwise need to treat many more participants for a much longer time, costing much more money to find treatments for disease. If funded by NHLBI, SANDS

ECHO will continue to look at these surrogate endpoints, as well as keep track of any heart and artery related problems that may develop over the next 5 years in the SANDS participants.

Through the hard work of the participants and clinic staffs in each of the 4 SANDS field centers (Phoenix and Chinle, AZ, Lawton, OK, and Rapid City, SD), we now know that the lower blood pressure and blood lipid goals can be achieved in a research study. If these lower target levels are helpful, we will need to find out if they can be reached in the regular clinic setting. This is a major goal of SANDS ECHO. SANDS has shown that excellent control of blood pressure and blood lipids can be achieved by our participants by faithfully taking the medications prescribed for them by their physicians and healthcare providers. Now the investigators hope to show through SANDS ECHO that maintaining blood pressure and blood lipids at the levels achieved during SANDS will stop or even reverse hardening of the arteries and result in fewer heart attacks and other devastating kinds of cardiovascular disease. We hope all of the SANDS participants will participate in SANDS ECHO and continue to show the value of excellent control of blood pressure and cholesterol levels.

SHS

SHS Arizona Participant States: "Study Good Learning Experience"

Katrina Moffett joined the Strong Heart Study (SHS) during the family phase. When the Arizona recruiters came to talk to her about the fifth phase of SHS, she was eager to participate. She was curious to see if there were any changes since the last visit several years ago. She said the recruiter, Bernie, explained everything about the study very well. She initially participated in the SHS because some family members suggested it was a



Above: SHS Arizona participant Katrina Moffett.

good learning experience. Her experience the first time was very positive, as was her most recent experience in phase V. She said that she was greeted with enthusiasm, and the staff showed great respect for her and her family. She said the staff explained every part of the visit in a manner that she could understand. She said she would do it again, and she would recommend anyone that is eligible for this phase to complete it as well.

SHS

SHS Oklahoma Participant Eager to Participate in Phase V Exam

"I love Strong Heart (SHS)," said Lorene BigBow Horse, affectionately known as Ella Faye. "It is something wonderful."

This is quite a compliment to the SHS coming from such a respectable person in the American Indian community of southwest Oklahoma. The SHS is fortunate to have participants like Ella Faye who are so dedicated to the health of all people and also to the SHS's goals.

Ella Faye was born October 17, 1925, in a teepee on her father's allotment south of Carnegie, OK. She is the descendent of BigBow, a Kiowa chief, and she is the daughter of Abel and Agnes Aung-Kotoye BigBow. Although she was the youngest of her siblings, she was the only one in her family who accompanied her mother and grandmother as they worked in the community as midwives and physical healers using time-tested native practices.



Above: SHS OK participant Lorene BigBow Horse.

"I had older sisters that could have been taught, but they said that I was the only nosey one, so I learned by watching and listening. I've seen lots of miracles happen so I know it was a good thing," Ella Faye said.

Ella Faye has not had an easy life, but has enjoyed every day. Her sense of humor and easy flow of laughter fill a room with fun. Her patients continue to come from all walks of life from border to border, coast to coast. She works with all races. She says that her Creator-given gift is for all people. She still lives by the inspiring words her father spoke from his deathbed. "Your gift is like a tree," he said to

Ella Faye. "You will branch out."

Ella Faye continues to give to others and branch out. She also shows a strong appreciation for others in the medical community like those from the SHS.

"That time when you all came out here to my home," she said. "It was something wonderful. When you all left my home that day after SHS examined me, I felt so good. When I saw that SHS truck driving down the road, I asked Lahoma, my daughter, to stop the car. I want to pray for those girls and that doctor. I know the Lord will bless all the efforts of SHS."

Diabetes is beginning to affect Ella Faye's family. She says she has always fed her sons and daughter well. She raised them on the north side of the Wichita Mountains where she literally lived off the land. Her late husband, Stanley, would hunt wildlife. She said they ate deer, small game, and on special occasions, elk. She said her

favorite foods are Chicken Fried Elk Steak and fresh fish.

With seven sons, one daughter, 17 grandchildren, and many great-grandchildren, Ella Faye has lived to see five generations come after her. She shows genuine appreciation for her life and those around her, and she also shows concern for her family and those in her community who have been affected by illness.

"I want all of our people to go to SHS," she said. "I wish we had SHS a long time ago. Maybe more of us could still be living."

SHS

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Strong Heart Study Dakota Participants Discuss Impact Study Has On Their Lives

"I think that Strong Heart Study (SHS) is doing something that should have been done years ago. There are many people we know, family members, that have passed-away and we did not know why." Louis Jewett, an original SHS cohort participant, along with his daughter Mona DuBray, gave their thoughts and opinions about the SHS. Mona also participated in Phase IV of the SHS and encouraged many family members to participate as well. Louis said that he feels strongly about the community's need for the SHS, and he talks about his own experiences with the program. He remembers when he was a child and a relative who knew about health came to visit.

She treated his siblings including a brother and a set of twins. "She used the information that she knew at the time, it was research that she had learned from others and from nature. We have always known that genetics is a part of family health but now we have better tools to understand genetics and we should take advantage of them."

"My wife was insistent that we got involved with the program. I went in to do the ultrasound and they found that I had a 95% blocked carotid. The Strong Heart staff sent me over to IHS to get assistance to repair

this and I was sent to Rapid City and had surgery right away."



Above: SHS Dakota participants Louise Jewett and Mona DuBray.

One point that Louis and Mona said that they liked about the SHS is that the field staff was made up of community members. Louis stated that he knew Lillian Brown and every time he sees her, she knows him. "She got a lot of us involved in the study."

Mona agreed that the SHS had a big impact in their lives. "It was a miracle that the program did the test when they did. My dad didn't have any symptoms."

Mona said that she would like to see the program continued for further study about cancer and other illnesses.

Mona said that the incentive program made it easier for people to participate, especially for those who have far to travel. "I think that the incentive program really helps. Some people struggle just to travel into town."

"It's a great thing. Maybe I wouldn't be here today without SHS." Louis said. "I believe that by continuing SHS that it will help others as well".

SHS