



STRONG HEART STUDY

INVESTIGATING CARDIOVASCULAR DISEASE
IN AMERICAN INDIANS

newsletter

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Preparing for the next phase of SHS

It's a busy time at the Strong Heart Study. The National Heart, Lung, and Blood Institute (NHLBI) provides funds to the SHS through grants, and we are reaching the end of our current grant, Phase V. However, we are looking ahead to Phase VI. We wanted to use this issue of the SHS newsletter to keep you updated on what is going on at the Strong Heart Study and what we hope to accomplish in Phase VI. The cooperation we share with the SHS participants and the tribes is very valuable to us, and we feel it is important to let you know what is happening here at the SHS.

Although we have been going strong since 1988 (that's 22 years!), every so often we have to apply for more funding. This process brings about a lot of work at the SHS. We must submit an application, which we begin planning more than a year in advance of the due date. In fact, it's something we continually think about every day. While we find answers to our research questions, we come up with even more questions. In our application, we let the NHLBI know that we want to continue our research so we can continue to answer our questions about heart disease in American Indians.

"It's a lot of work," said Lyle Best, principal investigator at the SHS Dakota Center. "The first step is to figure out what kinds of questions need to be answered and what questions should be answered."

Dr. Best said that the SHS investigators then review available literature and assess the current SHS data. The goal of the proposal is to convince scientists at the NHLBI that we need to continue this research and why we should use government money to continue to fund the SHS.

"There is an extremely competitive and detailed renewal process," said Barbara Howard, SHS Arizona Center principal investigator. "It involves submitting a scientific plan, which is very complex. The difficult part of the application is to present a detailed, in-depth, and descriptive explanation of what we are trying to do in only 12 pages."

However, Dr. Howard pointed out that the submitted document actually consists of more than the 12 pages of the application. Many other documents must be submitted like a budget and justification for the budget, biographical information about everyone involved in the study, letters of support, and more detailed explanations about the exams and genetic research.

Despite our best efforts to be fully prepared when the grant submission deadline approaches, you can bet we are still working around the clock up until the deadline to ensure everything is perfect. The SHS means a lot to us who are involved with this research. The SHS is never "just a job" for us. The SHS is one of the most significant heart disease research projects in the world. SHS data have provided important and groundbreaking information about heart disease in American Indians. While the data prove invaluable to research about American Indian health, scientists in other countries around the world use the data to help their own populations, as well.

The value of your participation in this endeavor cannot be underestimated. You are helping save lives! By participating in this study, answering the questionnaires, and taking the medical exams, your information has helped improve the quality of life for American Indians. The data resulting from your participation will continue to ensure better health for many future generations, too.

"Strong Heart participants are incredibly generous with their time," said Shelley Cole, a principal investigator at the SHS Genetics Center. "There wouldn't be a Strong Heart Study without the dedication of our participants."

Did you know that health care providers like the Indian Health Service and tribal health programs use SHS data to develop their own health care delivery, education, and prevention strategies? You, our participants and friends of the SHS, make this all possible. Because of you, we have a Strong Heart Study, and you motivate us to find the information and research to give American Indians the best health possible. Your health is our motivation, and we want nothing more than to find the answers to the chronic health problems like heart disease and diabetes that have such profound effects on the lives of American Indians. Even if you do not have one of these diseases, you might know someone who does. Chronic diseases affect many lives. When we can find better prevention and treatment strategies, the entire community benefits.

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The Plan for Phase VI

We believe Phase VI of the SHS will bring us even more answers about the prevention and treatment of heart disease as it relates to obesity and diabetes. Phase VI has three main components. One component is continuing the research from the previous phases. The other two components involve further genetic research and more evaluations so we can expand our knowledge on the early stages of heart disease. Because you and your family have participated in this study, we can focus solely on issues affecting American Indians and search for treatment and prevention strategies specific to American Indians based on genetics and environmental factors.

“What is extremely interesting about Phase VI is that we are going to be doing some new measures that have never been done before and never in American Indians,” said Dr. Howard. “They are very safe, but they are very complicated because they are going to tell us a lot about the liver, about fat, about blood pressure and its regulation, and the heart and its regulation. Another valuable thing about this next phase is the long follow-up of the initial group of participants that allows us to make analyses of the longer impact of biological and behavioral risk factors on chronic disease and how patterns of heart disease change in American Indians.”

Furthermore, Dr. Howard said that our genetics team has some very innovative and exciting new approaches to try to uncover genes that will help develop new strategies for prevention and treatment.

In the June 2009 SHS newsletter, we gave you a brief overview of what we hoped to include in the Phase VI grant application. The following is a more detailed outline of the main features of our Phase VI application. As always, we welcome any questions you have about the new funding proposal or any other questions you have about the Strong Heart Study.

Focus 1: Genetics

In Phase VI, the genetics studies will focus on two areas:

- Investigators have previously identified regions of chromosomes where it appears changes in DNA that are inherited can affect risk factors associated with heart disease, such as heart rate, blood pressure, size of the left ventricle of the heart, etc. Investigators propose to follow-up these results by doing more genetic studies to try to identify the actual gene(s) involved. We also will test to see whether or not environmental factors interact with these genes to modify their effect. An

example would be looking at the data to determine if smoking cigarettes enhances your chance of being at more risk for having an increased heart rate if you have a certain form of a gene.

- In the second approach, we will look at levels of gene expression in individuals undergoing the liver imaging studies to determine which genes have expression levels that correlate with the amount of fat in liver as well as other heart disease risk factors.

Focus 2: Broaden our understanding of what links obesity, diabetes, and heart disease

In the past, the SHS examinations focused on examining the heart. Based on years of research from the SHS and research from other scientists, we found a connection among obesity, diabetes, and heart disease. We want to further examine this connection by re-examining SHS family members and focus on learning more about the earlier stages of heart disease. This will be done in two ways:

1: Perform an MRI of the liver, abdomen, and abdominal aorta. An MRI is a painless, non-invasive image. MRI stands for “magnetic resonance imaging” and it does not use any radiation to capture the images. The MRI will allow the

physicians to measure the amount of fat in the liver. We believe this is the key to understanding what leads to high blood sugar and high blood fat. We hope this understanding will bring better treatment options and prevention techniques. As we compare these results with each participant’s previous exam results, we will also be able to assess genetic determinants.

2. Perform a cold pressor test. This test involves the participant dipping his hand into ice water for 150 seconds. We take blood pressure measurements before, during, and after the test, but one of the machines used to measure blood pressure for this test is much more sophisticated than the regular blood pressure machine. This machine measures how blood flows through the vessels, and we believe this information will tell us why blood pressure goes up in some people and how blood pressure medication can work better for an individual.

Focus 3: Continue to monitor data about heart disease in SHS participants

We will continue to monitor the death rate from heart disease and how often heart disease and related diseases occur in the original SHS participants. Additionally, we will continue to study the inheritance of risk factors in American Indian families.



Health Board Makes Trailer Available for SHS

At the SHS, we have yet one more reason to be grateful to our Anadarko and Lawton, Okla. community. We depend greatly on our community partnerships throughout all three field sites, and recently, our partners and friends in Oklahoma really stepped up to help us in a time of need.

In the beginning, the SHS Oklahoma field office occupied space provided by the Indian Health Service (IHS) on the third floor of the Lawton Indian Hospital, an arrangement with several advantages. However, in 2005, expanded hospital services required the SHS to relocate. Unfortunately, repeated efforts failed to identify satisfactory space anywhere near the hospital and the need for research space became a serious problem. Finally, two office rooms in the nearby hospital snack shop were kindly provided, in which SHS staff could carry out necessary office functions. While SHS staff members were grateful to simply have a place in which to locate, the SHS outgrew the space and we continued to search for an alternative.

Finally, a solution seemed possible.

The IHS Special Diabetes Program no longer needed a trailer it had used, and Mr. Hickory Starr, the CEO of the Lawton Service Unit, suggested it might be possible to use it for the SHS. However, efforts to secure its use brought unforeseen challenges that seemed to loom larger than conducting the study itself. Once one challenge was overcome, another was poised to take its place. Through the gracious efforts of a number of individuals including Mr. Hickory Starr, Claire Banks RN, the Director of the Special Diabetes Program, and Mr. Gary McAdams, the then Chairman of the Health Board, the SHS staff were finally able to move into the trailer in 2007. However, it wasn't until the end of 2009, after much discussion, study, goodwill and negotiation, that all terms of the deal were finalized. The administrator of the Southwest Intertribal Operation and Maintenance Program (O&M Program), Mrs. Mary Shane, proved to be a key person and Mr. Lupe Gooday, a member of the Ft. Sill Apache Tribe and recently installed Chairman of the Health Board, played a significant role, as well.

The extent of the complexities arising from working with several governmental and non-governmental organizations, seven sovereign tribes, the University of Oklahoma, the SHS itself, and the O&M Program in Anadarko can well be imagined. What one might have expected to be a routine matter turned out to be a series of rather difficult challenges, but through great perseverance and patient negotiations, success was finally achieved.

According to Dr. Everett Rhoades, senior consultant to the Study and a member of one of the

tribes, the achievement of the agreement between the Board and the Study was a significant accomplishment from two perspectives.

"This struggle illustrated the unusual dedication and persistence of Drs. Lee and Ali in pursuing the means to conduct research," Dr. Rhoades said. "I hope this example of extra dedication would be recognized by the National Heart, Lung, and Blood Institute, which funds the research."

Dr. Rhoades also said that it was even more noteworthy that the Health Board, representing the seven tribes, went out of its way to make the trailer available, marking a major contribution to the research effort. Such a contribution, according to Dr. Rhoades, is not only a tribute to the enlightened approach to community research by the SHS investigators but illustrates the willingness of the Tribes to contribute to the research effort.

"We are grateful to IHS for providing office space for our research studies in Anadarko and Lawton for all these years," said Dr. Tauqeer Ali, Field Director of the Strong Heart Study, the Balance Study, and the Oklahoma Center Principal Investigator of the newly funded Strong Heart Stroke Study. "We appreciate the support from the local tribes for allowing us to use their trailers in Anadarko and Lawton once IHS ran out of space in its facilities for SHS. This unique collaboration of SHS, tribes, and IHS has been the key in conducting successful research with a common goal of improving the health status of people in our communities".



Above: Mr. Lupe Gooday, Chairman of the Southwest Oklahoma Intertribal Health Board, outside the trailer housing the Strong Heart Study at the Lawton Indian Hospital. The Health Board not only made the trailer available but provided a means whereby the Study could provide insurance for the building.



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Strong Heart Study

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Meet the Principal Investigators

In the first story of this newsletter, you heard from some of the SHS Principal Investigators (PIs) about our application to extend the SHS. A Principal Investigator is the lead scientist working on a research study. The SHS is so large and complex that we actually have five PIs, one for each major area of the study. You might expect conflict and competition with five people in charge, but that is not the case if you ask any of our PIs.

“There is an amazing amount of cooperation among the PIs at the SHS,” Dr. Howard said. “We always work toward our common goal. We all want the maximum benefit for the community. Our commitment is to the participants and the community.”

Every PI on the SHS agreed with Dr. Howard. They all expressed their gratitude to each other and how lucky they are to work with one another.

Chances are that you have met at least one of the Principal Investigators or have seen them in the community. If not, we want to take this opportunity to introduce you to them. Over the next several newsletters, we will profile one or two SHS PIs. If you recognize any of them in your community, we hope you’ll introduce yourself. They will be happy to meet you.

In this issue, we introduce you to Dr. Lyle Best, Principal Investigator of the Dakota Center. In future issues, we will profile Dr. Barbara Howard from the Arizona Center/Core Laboratory, Dr. Elisa Lee from the Oklahoma/Coordinating Center, Dr. Shelley Cole from the Strong Heart Family Study Center in San Antonio, TX, and Dr. Richard Devereux from the ECG and Ultrasound Reading Center in New York.

Dr. Lyle Best



At the Strong Heart Study, Dr. Lyle Best serves as the Principal Investigator of the Dakota Center, but his professional life and personal life extend much further than that. Dr. Best is also a family physician, scientist, teacher, mentor, father, husband, cattle rancher... the list goes on. At the SHS, he supervises the

scientific aspects of the study, which include ensuring that the collection of data is accurate and unbiased, and he also ensures that the participants’ rights are guaranteed. This is obviously a big and time-consuming, responsibility, yet Dr. Best still makes time for his other professional passions, which include researching the genetic influence on preeclampsia and working with students at Turtle Mountain Community College, working as a family practice doctor one day a week in his local

community, and teaching family practice resident physicians in Minot, ND.

Dr. Best’s roots are in North Dakota. He and his family have left their home state of North Dakota a few times to pursue his professional aspirations, but he always returned to North Dakota where he and his wife raised their three children. Dr. Best speaks fondly of his community and his children, and it is obvious that he takes great pride in both. Dr. Best said that the connection he has with his community continues to inspire his work with the Strong Heart Study. He said that he hopes the research he’s involved in provides answers, cures, and hope to his community, neighbors, and friends who suffer from diabetes and heart disease.

When Dr. Best is not at work, he is likely to be found working with his cattle, in his shop welding, or traveling with his wife.