



STRONG HEART STUDY

NEWSLETTER

INVESTIGATING DISEASE IN AMERICAN INDIANS

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SHS FAMILY STUDY ACHIEVES INITIAL GOALS

The Strong Heart Study achieved another milestone at the end of 1997 with the examination of 300 or more family members in each of the three centers. Clearly, this remarkable accomplishment could only have been achieved through the full cooperation, interest, and good will of the many families invited to participate in this groundbreaking work. All of the SHS investigators and staff extend their heartfelt thanks to the families.

The numbers for the Family Study at each center were as follows: Arizona examined 315 participants representing 12 families; Oklahoma examined 310 participants representing 11 families; and South Dakota examined 303 participants representing nine families. The numbers of people examined from each family varied in this preliminary or feasibility study (also called a pilot study). For example, in Oklahoma the number volunteering from each family ranged from 21 to 44. The numbers of individuals reported above may change slightly as a few more key individuals are examined in the first quarter of 1998.

Certain individuals are still needed to fill in gaps in some family trees to link branches containing the currently examined members of a family.

Dr. Jean MacCluer, population geneticist from the Southwest Foundation for Biomedical Research and principal investigator for the family pilot study, noted that recruiting for a family study is somewhat different from traditional epidemiology studies like the original Strong Heart Study.

In a family study the value of the data for an individual is dependent on who else in the family is examined. This dependence changes the conduct of recruiting and requires a great deal of cooperation between the families, the field staff, and the family study analysis center staff. Fortunately, that cooperation was very high in this pilot study, and all centers were able to achieve study goals. Because of the complexity of this study, the field staffs at all 3 centers deserve special recognition for their dedication to completing the project.

Richard Fabsitz, the National Heart, Lung, and Blood Institute Project Officer for this study, was equally laudatory of the study staff. He expressed his appreciation for the continued enthusiasm of the SHS staff to meet whatever goals are placed before them in furthering research on cardiovascular disease in American Indians. He also expressed his appreciation to the communities, families, and individuals

COOPERATION BETWEEN SHS PARTICIPANTS AND STAFF ARE CORNERSTONE FOR STUDY'S SUCCESS

for their commitment to participate in the Strong Heart Study.

"I am optimistic that the relationship of cooperation and trust between the SHS staff and the communities will continue to provide useful insights into the underlying causes and potential treatments of American Indian health problems that are being addressed by the Strong Heart Study," Fabsitz said.

The potential now exists to propose an expansion of the Family Study to include more families from each center so that we may learn more about the genetic and environmental determinants of disease in this population.



CONFIDENTIALITY OF INFORMATION USED IN THE STRONG HEART STUDY

People who take part in research studies often express legitimate concerns about the confidentiality of the information gathered about them. They want to be certain that their test results are available only to the people who need them and only for the reasons described in the consent form. All SHS staff sign confidentiality pledges and are committed to maintaining the confidentiality of participant data.

The clinic gives each participant in the Strong Heart Study a six-digit identification (I.D.) number with which the clinic labels the various samples. This number is the *only identifying marker* for the samples.

When the SHS central laboratory (the Penn Medical Laboratory in Washington, D.C.) receives the blood, technicians inspect it prior to conducting tests. A record is made in the laboratory computer that includes

the SHS I.D. number and information about the sample, such as the date of receipt, the type of sample (blood or urine) and the tests that will be run on it. The laboratory never learns the name of a person who donated a sample. We guard the laboratory computer system behind locked doors and require passwords to open the computer records. Only laboratory technicians have the passwords.

We send the results of the tests back to the SHS Clinic and to the SHS data center in Oklahoma City, labeled only with the I.D. number. The *only* time the participant's ID number is matched with their name is when the clinic nurse writes the letter about the results from the lab work done on submitted samples. The SHS clinic also gives the results to the participant's doctor, if the participant requests it.

The Strong Heart Study is concerned about confidentiality. We want the data from this study to benefit the American Indian people. The efforts taken to protect the identities of individual SHS participants are thorough, yet still allow us to use the data to help improve the health of Native Americans and their communities.

MAYO CLINIC STROKE RESEARCH PROJECT LINKS EFFORTS WITH SHS

Stroke is the third most common cause of death, the most important cause of severe disability, and the most common life-threatening neurological condition in the United States. Our national health care efforts have been directed at the treatment of first-time and recurrent strokes to reduce fatality and increase the recovery and independence of survivors. Since stroke patients need both acute care and long-term therapy, there is good reason to identify and treat patients who may be at high risk for stroke. Even greater benefits may be realized by reducing the level of stroke-related risk factors in the population.

The Rochester Epidemiology Project and Mayo Stroke Center currently offer the only resource in the United States for determining how often strokes happen, how many people in a community suffer from stroke, and risk factor data based on the total population in a community. The long-term goal of the Mayo Stroke Center is to utilize the Rochester resource to provide information that will lead to stroke prevention in the population.

One of the few shortcomings of the Rochester epidemiology resources is that the population contains only a 4 percent minority population and therefore it's not clear if the results of our studies can be applied to those individuals.

The Strong Heart Study has been designed to greatly enhance our understanding of health care needs among American Indians. The current

proposal involves a collaboration between the Strong Heart Study team and Dr. David Wiebers and colleagues at the Mayo Stroke Center.

This cooperative effort will not require additional testing or duplication of the work that is already part of the Strong Heart Study. However, the experience and expertise of this group in the areas of stroke and epidemiology should be of assistance to American Indians and to the Strong Heart Study investigators by expanding the design and statistical analysis in a way that would allow a valid comparison of the Strong Heart Study stroke data to similar data collected over the years from residents of Rochester, Minnesota. Our Mayo colleagues will assist with making stroke diagnoses and providing a stroke-related resource for questions which arise. They also will assist with data collection and analysis regarding stroke-related disability and death.

The comparison of stroke rates and the effect of various risk factors on those rates between American Indian populations and residents of Rochester, Minnesota will help establish, for the first time, population-specific guidelines for the prevention of stroke among American Indians. All involved are extremely enthusiastic about developing such guidelines and are convinced that this will be something which could be of great value to American Indian people.

Head Start Children Visit Arizona SHS

Pre-schoolers given tour and tips on healthy living

Have you ever thought about what it would be like to explain to a young child what you do and have them truly grasp the meaning?

That's what happened when the Head Start Class at District #6 of the Gila River Indian Community invited the staff of the Strong Heart Study to visit their class.

This past summer, two of the study nurses, Betty Jarvis and Judy Bergman, along with the visiting dietician, Ellie Zephier from the Aberdeen IHS, spent some time with a small group of pre-schoolers from Gila River Indian Community and their instructors.

All sat together on the carpeted floor and the children's eyes showed their alert readiness to take in information. When the discussion got to the heart and its circulation in the body, a little boy raised his hand when prompted by a question about the heart and what it did. We were proud and amazed that someone so young could reply with, "The heart pumps the blood!" They held up their fists

when we said, "Your heart is about the size of your fist; can you make a fist for me?"

After talking some more about the heart and its functions,



Gila River District 6 Head Start teacher Anne Garcia and students (l - r) Frank Sunn, Soinya Pablo, Devin Sundust, and Mallory Manuel.

we shared ideas on how to keep the heart strong and healthy. The children participated eagerly and had some knowledge of what keeps people healthy. They knew we need to eat fruits and vegetables and get some exercise. We then had the children listen to their own hearts with our stethoscopes.

Their eyes brightened as they first heard the sounds of their heart beating. They became quiet, marvelling at the experience of hearing their own heart pumping. One little boy asked me "Can I hear mine again?"

After the presentation, we went in pairs to the Strong Heart Study Mobile Clinic Van for a brief tour. The teacher told us that the children often asked about the heart van parked outside the Head Start classroom.

The children were very interested in the inside of the van and had some more questions after seeing it.

We explained the ultrasound "machine" that takes pictures of the heart and blood vessels. Most of the children were very quiet during their visit to the clinic van; you could see the wheels turning inside their heads as they experienced something new. Following the tour we took the children back to the classroom and presented them and their teachers with a Strong Heart Study cap.

Afterward, the SHS staff talked about our visit and wondered if there were any future doctors, nurses, or other health care givers in this group of energetic and bright "little people."

What a thrill to be able to share a tiny bit of what the Strong Heart Study is about and come away knowing these children now have some idea of the importance of learning more about hearts and taking good care of them.

MAYO CLINIC CONGESTIVE HEART FAILURE STUDY ADDED TO SHS AGENDA

As part of the Strong Heart Study, there have been careful medical evaluations aimed at trying to learn more about the extent of cardiovascular and lung diseases among American Indian peoples. We hope this information will provide valuable clues that will enable us to improve the health and welfare of American Indians.

As an extension of the Strong Heart Study, Dr. Richard Rodeheffer of the Mayo Clinic in Rochester, Minnesota, has proposed a cooperative project that would be directed specifically at improving the treatment of congestive heart failure.

Congestive heart failure (CHF) is one of the most common forms of heart disease and causes disability as well as a reduced life expectancy. It results from weakness of the heart muscle and is seen more in those who are older, who have had heart attacks, diabetes, or high blood pressure, and among those who have been cigarette smokers. Recent information suggests that the frequency of CHF is increasing and that it is one of the most common causes for hospitalization among older persons.

Fortunately, new medications are available to treat symptoms and increase life expectancy for patients who have heart muscle weakness and heart failure. One of the problems we face currently is identifying those who have heart muscle weakness *before* they develop symptoms of heart failure. Patients with mild to no symptoms may not be diagnosed with congestive heart failure and, thus, are not as likely to benefit from available treatments.

Therefore, an important goal in the care of people

with CHF is to develop simple ways of identifying those who could benefit from the treatment. We recently have learned that measuring the level of certain substances in the blood (atrial peptides) may help us identify those who have heart muscle weakness. If a blood test could be used to diagnose CHF at an early stage in a person, that person could be offered treatment that could help keep the disease from getting worse.

To accomplish this, we plan to analyze blood samples taken during Phase II of the Strong Heart Study in the Dakota center. Blood was stored during this part of the study for future analyses such as this. Analyzing blood samples for these markers is consistent with the overall goals of the Strong Heart Study and will be related to information from the questionnaires, physical examination, and echocardiogram. SHS participants from the Dakota Center whose blood may be tested will be notified by mail. If they do not want the tests done, they can notify Dr. Thomas Welty or Alan Crawford at 1-800-854-8854, extension 401 or 319. The studies at the Mayo Clinic will be a part of a larger effort involving a similar analysis of people living in Olmsted County, Minnesota. Combining the information from the Strong Heart Study with the information gathered in Olmsted County will greatly improve the value and accuracy of the study.

If these efforts allow health care workers to identify and diagnose congestive heart failure in people with a simple blood test, the opportunity to provide early treatment and prevention strategies could ease suffering and save lives.

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