



STRONG HEART STUDY

Cardiovascular Disease in American Indians

NEWSLETTER

August 1994

Volume 6, Number 3

STRONG HEART STUDY PHASE II SURPASSES 1,500 EXAMINATIONS

The Strong Heart Study exceeded the 1,500 examination mark during June 1994, to complete the first third of the goal of re-examination of the participants in the first examination. During June, the Arizona and Oklahoma centers examined 54 participants, each for a total of 538 and 582, respectively. The South Dakota center, having fallen off the pace due to numerous difficult circumstances, demonstrated a strong commitment to catch up, with 80 examinations in June and a total of 400 by the end of July. We applaud the South Dakota staff for the high monthly total that demonstrates their commitment to overcome adversity and begin to bring the South Dakota center up to the level of the other centers. All centers should be striving to do more, since each center is short of the goal of 606 examinations forecasted by this time.

While quantity is an important measure of how well the study is progressing, quality is equally, if not more, important. Dr. Paul Enright reports that the pulmonary function tests submitted to the central reading laboratory at the University of Arizona have greatly improved and that all centers are achieving high-quality readings from participants. This is quite an accomplishment, since most of the examination participants have never had a pulmonary function test, and it requires a maximal effort that is not a normal activity of everyday life. The site visits by Pam Boyer-Pfersdorf were very helpful in improving the quality of these measurements. Equally good news

comes from Dr. Devereux at the echocardiography reading center, who reports that the percentage of usable examinations for the highest priority measurements from echocardiography is exceeding the highest expectations.

Last month another important task was completed; the last morbidity and mortality events from the first examination were resolved by the review committee. As a result, scientific papers that were dependent on these results may now be completed. For those who have worked so diligently to track down information that would allow these events to be properly classified, it is welcome news. This is very tedious work, requiring great attention to detail and perseverance to locate information that may not be readily available. This work is essential to the involved process that is required to properly classify who has had heart disease, and it is greatly appreciated.

This is a complex time for the Strong Heart Study, because there is a need to concentrate on many tasks that all require attention at the same time. The second examination is ongoing, issues surrounding Phase I data are still being resolved, scientific papers and presentations must be completed, and everyday problems are continuous. Strong Heart Study staff members should recognize that each person has an important task that contributes to the success of this study. It will succeed because all members of the team are effectively doing their part. It is pleasing to see that we are well on our way toward completing the second examination of this important study.

STRONG HEART STUDY PROVIDES A MODEL FOR COMMUNITY INVOLVEMENT IN RESEARCH

The Strong Heart Study was the first study funded by the National Heart, Lung, and Blood

Institute (NHLBI) that targeted specific ethnic groups in rural communities. This was a milestone in medical research, because almost all previous studies of cardiovascular disease in the U.S. had focused on caucasian groups in urban or suburban settings. Thus, the Strong Heart Study had to develop new strategies for recruitment, conduct of examinations, and retention of participants.

From its inception, the Strong Heart Study investigators decided that the members and leaders of its 13 American Indian communities would be involved in all aspects of the study. This began with the study design. Community members were consulted concerning the components of the examination and the convenience of various locations for clinics. All questionnaires were reviewed by the tribes for both content and cultural appropriateness. One relevant example of the utility of this review was our recent attempt to institute questionnaires to assess depression and anxiety. Extensive pilot testing by American Indian community members indicated that the questionnaires were not appropriate in their present form, thus avoiding time being wasted in the collection of invalid data.

The communities involved in the Strong Heart Study have provided invaluable assistance in the enumeration of the eligible population. Individuals who had resided in the communities for many years had accurate knowledge concerning individuals who had moved or were deceased.

Community members have also played major roles in recruitment efforts at all sites. Their knowledge of potential participants, coupled with their enthusiasm concerning the importance of the Strong Heart Study examination, resulted in high rates of participation for Phase I. This recruitment assistance has been even more important in retaining participants for Phase II examinations.

Members of the community have also been employed in the exam clinics. Their work has been particularly valuable in administering the questionnaires and diet interviews; they were aware of how to phrase questions and gain the confidence of the participant, thus acquiring more complete and accurate data. Many of the employees from the Indian communities have been young people who have been so stimulated by their experience that they are pursuing educational or employment opportunities in health-related careers. Finally, information collected during the examinations has been provided to each community for use in planning health programs.

In summary, the success of each stage of the Strong Heart Study has been dependent upon the input and support of the American Indian communities. The Strong Heart Study is now recognized as a leader in the concept of community involvement in research studies and has been recognized by the NHLBI Committee on Minority Populations for its community involvement. We hope that all future studies will take this approach.

GALLBLADDER EXAMINATION RECEIVES ADDITIONAL ATTENTION

Participants and staff recognize that the gallbladder examination is one of the new measurements added to the second examination. It is funded through an interagency agreement in which the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) provides funds to the NHLBI to complete this Strong Heart Study test. In the early experience of the second examination, it became clear that the measurements were not meeting expectations. To address a number of issues surrounding the gallbladder measurements, Dr. Hill from the central reading center at George Washington University Medical Center in Washington, D.C., and Dr. Jay Everhart from NIDDK held a training session in Phoenix on June 23, 1994. At this meeting, ultrasonography technicians from the Strong Heart Study centers

had a chance to exchange information with reading center personnel and to learn new techniques that might be more effective at increasing the quality of the images. The meeting was considered very productive by all who attended. As a result, new methods are being employed that will make it easier on participants and technicians as well provide improved images to the reading center. Another result of the meeting was the decision to acquire additional electronic components for the ultrasonography equipment that will sharpen the images on some participants whose gallbladders are challenging to visualize. Images of the gallbladder provide an assessment of gallbladder disease, usually gallstones, which appears to exist with a higher frequency among American Indians.

DAKOTA CENTER RECRUITMENT

Strong Heart Study staff at Eagle Butte and Pine Ridge are taking advantage of the good weather to increase their recruitment. In the month of June, 80 participants were seen in both centers; and 65 participants were seen in July. Eagle Butte team members are: Marsha O'Leary, RN, Ramona Simon, RN, Kurt Schweigman, Health Technician, and Lillian Brown, Recruiter. The trailer that was rented for the study has worked out extremely well and provides adequate space in which to conduct the exams. Pine Ridge team members Juanita Mauer, RN; Ann Weston, Health Technician; Patsy Foote, Health Technician; and Dora Watson, Recruiter, are working efficiently in their new location, the old mental health social services trailer. This space became available when the new Pine Ridge hospital opened in March. As well as improving health care for the Oglala Sioux, the new hospital has an outstanding collection of over 190 Indian art objects. The hospital was dedicated on June 29, 1994, with a very successful open

house which was covered by the media. Helen Beaty has been busy performing gallbladder and cardiac ultrasounds for study participants. Arrangements are being made to obtain additional assistance with echocardiograms in the Dakota Center, since they must all be completed by April 1995, at which time the echocardiography machines must be returned to the heart institute. Beverly Blake, RN, FNP, Strong Heart Study Coordinator; Alan Crawford, PHA; Marge Grant, Administrative Support Assistant; and Barb Paulson, Clerk, have supported the ongoing work of coordinating the shipment of blood, copying charts, and reviewing morbidity and mortality records. Tom Bad Heart Bull provides administrative and financial support to the project on a regular basis. Ellie Zephier, RD, coordinates the nutritional aspect of the Strong Heart Study. The Dakota Center is making every effort to catch up to the other two centers in their completion of Phase II exams.

HABITAT FOR HUMANITY IN EAGLE BUTTE

Eagle Butte was invaded by over 1,000 Habitat for Humanity volunteers to assist homeowners in the construction of 30 homes. The volunteers included President & Mrs. Jimmy Carter. This was the first Habitat project in an Indian community and is one that should be replicated in other Indian communities where housing shortages are often acute and contribute to many health problems. Homeowners pay off no-interest loans for the cost of their homes, and their payments can then be used by the local Habitat chapter to build additional homes in the future. Austin Keith, Director of the American Indian Habitat Program, hopes that other tribes will follow the example of the Cheyenne River Sioux. Volunteers, including the Carters, camped out in a tent city that was set up on the school's football field. Habitat volunteers, Drs. Tom and Edie Welty, had luxurious accommodations at the Strong Heart Study trailer in Eagle Butte during the week.

Among the volunteers were over 30 physicians and nurses who set up round-the-clock first aid coverage at the work site and at the school campsite. Dr. Jeff Henderson, Clinical Director at Eagle Butte, and Dr. Dave Mulder, one of the IHS physicians from Pine Ridge, also volunteered for the project.

The tribe scheduled a special powwow to coincide with the habitat project, which included a special honoring of President & Mrs. Carter and Millard Fuller, Director of Habitat for Humanity International Foundation, the sponsor of the project. The 30 homes are constructed in a circle, with a playground in the middle, in accordance with the theme, "Circle of Hope." At the conclusion of the project, President & Mrs. Carter posed for a group photograph with the homeowners and work crews at each of the 30 homes. During the week, the Carters kept quite busy working on house #1.

FITZSIMONS ARMY MEDICAL CENTER WILL CONTINUE SUPPORT OF STRONG HEART STUDY

Under the leadership of Dr. Mark Dorogy and Dr. Richard Davis, the Fitzsimons Army Medical Center Cardiology Program will continue to serve as the ECG center for the Strong Heart Study as

well as continue monthly clinical consultations to the Aberdeen Area Indian Health Service. This continued support is very much appreciated by the Strong Heart Study Steering Committee and by the

staff and the patients in the Aberdeen Area.

ECHOCARDIOGRAPHY: A NEW WINDOW ON STRONG HEARTS

Beginning with the Phase II examination, ultrasound pictures of the heart and its pumping of blood have been taken on Strong Heart Study participants. These pictures, taken in the Strong Heart Study vans in Arizona and Oklahoma, as well as in IHS facilities in the Dakotas, have allowed many participants to see their hearts in action. The Strong Heart Study is the first study to perform echocardiograms at sites away from large hospitals and yet has still obtained accurate results in a higher percentage of participants than any other comparable study! These results are due

to the cooperation of participants and the skill of dedicated sonographers Joanne Carter and Michael Cyll in Arizona, Dr. Tauqeer Ali in Oklahoma, and Helen Beaty in the Dakotas. The hard work provided by Mary Paranicas and Drs. Mary Roman and Richard Devereux of the Reading Center at Cornell Medical College in New York City, has also contributed to the results obtained. Reports on the echocardiograms have been prepared for participants' medical records, and soon analyses of the results will start to yield important findings.

TRIBAL HERITAGE IN STRONG HEART STUDY PARTICIPANTS

There are 13 American Indian tribes or communities participating in the Strong Heart Study. They are the Pima/Maricopa in the Gila River Indian Community and Salt River Indian Community and Papago in the Ak-Chin Community in Arizona; seven tribes in southwestern Oklahoma: Apache, Caddo, Comanche, Delaware, Fort Sill Apache, Kiowa, and Wichita; and Devil's Lake Sioux from North Dakota and Oglala Sioux and Cheyenne River Sioux from South Dakota. The number of participants from the Apache, Delaware, Fort Sill Apache, Wichita, and Papago tribes were much fewer than any other tribes, with each having less than 100 participants. Participants from the Gila River and Oglala Sioux number well over 400 each.

had the lowest degree of Indian blood, with only 48% reporting full-blood; while Oklahoma was in the middle, with 74% reporting full-blood. On the average, participants belonging to the Delaware, Caddo, Cheyenne River Sioux, and Oglala Sioux have more interracial admixture, while the members of other tribes and communities have more intertribal admixture.

Participants from Arizona had the highest degree of Indian blood, with 98% of them reporting that they are full-blood. The Dakotas

Participants from Oklahoma and the Dakotas are reported to participate in traditional ceremonies more frequently than participants from Arizona. This may be because participants from Oklahoma and the Dakotas consider the powwow to be a traditional ceremony, while it is not a custom in Arizona. The findings in regard to culture and tribal heritage from the Strong Heart Study indicate that American Indians are not a homogenous group of people. The Strong Heart Study will provide an opportunity to determine whether there are factors that protect Indian people against heart disease or other health problems.

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