



# STRONG HEART STUDY

*Cardiovascular Disease in American Indians*

NEWSLETTER

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## EARLY STRONG HEART STUDY FINDINGS SHARED WITH INDIAN COMMUNITIES

At the end of the first examination year of the Strong Heart Study, investigators from the Study are meeting with community people at each of the clinic sites to provide a progress report, share early results comparing the three centers, and get comments from past and potential participants. In June meetings were held with the Salt River and Gila River Indian communities in Arizona, with staff from the NIDDK Diabetes Study in Phoenix, and also with representatives from the Lawton and Anadarko areas in Oklahoma. The Dakota center held three community meetings in July at Fort Totten, Eagle Butte, and Porcupine. Initial presentations were made by the Principal Investigators, Dr. Barbara Howard (Arizona), Dr. Elisa Lee (Oklahoma), and Dr. Tom Welty (Dakotas), and by the Program Manager, Richard Fabsitz (NHLBI). Other visiting Strong Heart Study investigators and staff participating in the question and answer sessions with the communities included Dr. Arvo Oopik, Director of the electrocardiogram reading center in Denver, Colorado, Dr. Peter Savage, Chief of the Clinical and Genetic epidemiology Branch, NHLBI, Dr. J. L. Yeh, Coordinator of the Coordinating Center in

Oklahoma City, Oklahoma, Paula Harper, study nurse from Arizona and Carol Mote, study nurse from Oklahoma.

The early results that were presented appear to confirm suspected differences among the centers in the prevalence of heart disease and its recognized risk factors. Also of interest to community members were results indicating significant differences among centers for demographic variables and measures of the observance of Indian culture and traditions.

Of particular value to the investigators was the opportunity to share impressions of and concerns with the conduct of the study. Community people had an opportunity to receive answers to many questions about the study and also provided valuable feedback to the investigators on procedures for the recruitment and the examination. In turn, the investigators stressed the need to maximize participation of community members during the second examination year so the study data will provide a true picture of each community for tribal as well as study use. All attendees found the interchange to be most helpful.

## FIRST YEAR OF EXAMINATIONS COMPLETED

The Strong Heart Study design provides for a two year period to complete 4500 examinations. This issue of the newsletter marks the end of the first year of that examination phase. By the end of June the numbers of examinations completed at each center are as follows: 650 in Arizona, 622 in Oklahoma and 537 in the Dakotas. Even though this number represents forty percent of the goal it is about 450 examinations short of the expected number at this time. While the examination staff members who have been involved since the beginning of the study are

becoming more efficient, recruitment after the initial excitement of the study appears to become more difficult. The investigators and staff members (especially recruiters) are urged to be innovative in their approach to "spreading the word" and to share their successful recruiting ideas with other recruiters within their centers and at the other centers. Currently various centers are trying different recruitment methods which include Saturday clinics, additional recruiters, and use of previous participants to recruit eligible friends and relatives. A genuine commitment exists

among the Strong Heart Study staff to achieve our goal at each center. The next twelve

months will be a challenge. Working together we will meet that challenge.

## DAKOTA VIGNETTES

The wide expanse of prairie, the endless horizon, extremes of temperature, and rapidly changing weather conditions combine to make a very challenging setting for a research study on three isolated Sioux reservations in North and South Dakota. Strong Heart Study staff have supported each other through some difficult times during the first year of the study and continued the forward momentum of the data collection stage. During the winter and spring of 1989/90 several situations are a testimony to the dedication of the staff, as follows.

A bitter cold spell two weeks prior to Christmas with temperatures minus 20-25<sup>o</sup> Fahrenheit and wind chill factors of 60<sup>o</sup> below slowed the study, but did not stop it. A few hardy participants managed to show up for their exams during this period. The staff drove through the bitter cold to recruit participants, provide transportation, and to come to work at the clinic. There were only several days when operations had to be shut down completely.

The icy roads took their toll on the study vehicles during the winter months. One day in January, Cecilia Fire Thunder had a fender bender on a sheet of ice and Pauletta Red Willow experienced a similar minor crash while driving her car to work. Fortunately, neither of the staff members was injured in these mishaps. Subsequently, their vehicles have been repaired.

Pauletta Red Willow was driving her pickup to Rapid City one Thursday this Spring and lost control of the vehicle. The vehicle overturned and the contents in the back of the pickup were strewn about. Although the pickup was a total loss, fortunately neither Pauletta nor her fiancé were seriously injured. They had the foresight to retrieve the laboratory specimens and drop them off at the Manderson Trading Post enroute to the Pine Ridge Hospital where they were evaluated and released. Pauletta contacted Dr. Welty and informed him of the whereabouts of the specimens which

were approximately 90 miles from Rapid City. Dr. Welty contacted the trader and requested that he keep the specimens in his refrigerator and asked whether someone would be driving to Rapid City the following day. The trader's wife was driving to Rapid City and agreed to bring the specimens to Rapid City in a cooler and to drop them off at Dr. Welty's office. The specimens arrived satisfactorily at the Medlantic laboratories and the results have been provided to the patients.

The Strong Heart Study team in Eagle Butte was examining participants at the Cherry Creek Clinic which is 50 miles from the Eagle Butte Hospital. On days when the exams are done, Gayle Moran, nurse practitioner, is the only health provider in the community. On one day a child who ingested kerosene was brought to the clinic for emergency care. Gayle instituted appropriate care for the child and arranged transport to the Eagle Butte Hospital.

The Pine Ridge Staff has completed 296 examinations in the Kyle, Wanblee, and Allen areas. The team has now moved to the Brotherhood Clinic at Porcupine where it will remain until the completion of the project. Homer Kills Back, the director of the board for the Brotherhood Clinic, is enthusiastic about the Strong Heart Study and was one of the first participants to complete the examination. The Cheyenne River Sioux Team completed examinations in the Cherry Creek area on June 20 and moved to the Red Scaffold Clinic where they will work for the duration of the summer. Three students from the Cheyenne River Community College, Amy Livermont, Debra Bruguier, and Betty Cook are funded by the 437 Scholarship program to help Mary Clown, the coordinator, Gayle Moran, RN, FNP, and Pauline Livermont, RN, with the study this summer. Upon completion of the participants from those areas, the team will move back to Eagle Butte and complete the other participants from smaller communities throughout the reservation.

## STRONG HEART DIETARY SURVEY TRAINING AND DATA COLLECTION BEGIN

Ellie Zephier, RD, MPH, is the principal investigator for the Strong Heart Dietary Study that is supported through an IHS research grant. As part of this study, 300 Strong Heart participants in Pine Ridge Reservation and 300 in the Oklahoma Area will be surveyed utilizing a questionnaire similar to the one completed on the Pima Indians. The dietary survey will provide valuable information on the possible contribution of diet to the rates of cardiovascular disease.

Training for the students was held at the Black Hills Training Center in Rapid City, June 4-8, with the assistance of Joanne Proulx from IHS nutrition training center in Santa Fe. The eight students attending the training are:

South and North Dakota:

Pine Ridge Site - William "Corkey" Howell and Lucia Choe, from Georgetown Medical School, Ann Marie Geary, Nutrition Student, Oregon State, Sarah Williams, Nutrition Student, Iowa State.

Fort Totten Site - Victoria Standing Elk, Nursing Student, Member Cheyenne River Sioux Tribe.

Oklahoma: Parman Ahdunko, Caddo, University of Oklahoma, Margie Deer, Caddo-Wichita, graduate student at University of Oklahoma, Marissa Horse, Kiowa, Oklahoma City University.

In addition, Karen Froehlich, RD, Diabetes Project Coordinator at Fort Totten, attended the training and will be conducting the dietary survey on 70 participants from the Fort Totten area. Steve Arity, RD, is providing on-site coordination for the students on the Pine Ridge Reservation. Janet Taylor, RD, is providing on-site supervision for the students in Oklahoma. All the completed dietary questionnaires will be sent to Ellie Zephier for review and data input at Aberdeen, South Dakota. The computer program used to analyze the data will produce reports on the nutritional content of the foods eaten by the participants in the survey so that comparisons between the various areas can be easily made.

## STRONG HEART STUDY COLLABORATES WITH NIH CLINIC AT HU HU KAM MEMORIAL HOSPITAL

In addition to the Salt River Clinic (see January 1990 Newsletter), Hu Hu Kam Memorial Hospital is a site for the Strong Heart Study in Arizona. This IHS hospital is on the Gila River Pima-Maricopa reservation and is located in Sacaton, Arizona which is approximately 40 miles southeast of Phoenix. The hospital is a modern 20 bed facility which was dedicated and opened in late 1988. It houses the NIH longitudinal diabetes research project which has been ongoing since 1965.

Fortunately, NIH graciously merged the Strong Heart Study exam with their patient examination which are conducted every Tuesday and Thursday. The NIH clinic not only provides an excellent facility, but also allows a sharing of experienced staff.

The Strong Heart Study Staff includes: Betty Jarvis, RN, Project Coordinator and Paula Harper, RN (see January 1990 Newsletter). Other staff are:

Wendolyn Johnson, a resident and member of the Gila River Indian Community (GRIC) - District 6, and a recruiter and driver for the Study. She also administers the personal interview at the clinic. Wendy, a mother of 2 children, Toni 12 and Ryan 9, describes herself as "easy going" and someone who enjoys her current employment. She has little free time for hobbies, but says she does enjoy eating "good food". Her career "dream" is to work in the computer science field. Wendy's persistence and patience has resulted in a record of personally bringing in the approximately 160 participants for the Study.

Stanley Miles, Sr., also a resident of the GRIC has been hired recently to assist in the recruitment and in conducting the personal interview for the project. His prior experience includes cooking in the NIH Metabolic Food Preparation Kitchen for approximately 15 years. Stan has 3 children and 3 grandchildren. His hobbies include guitar playing, reading and bicycling. Stan's career

"dream" is to further his education in the nutrition field.

The NIH staff at the clinic who assist with recruitment, scheduling, transportation, registration, interviews, phlebotomy, and measurements include:

Sonja Antone who has supervised the clinic for 24 years has made many invaluable contributions to the Strong Heart Study. She has 6 children, 9 grandchildren. Her hobbies include bowling, walking, and Indian Dancing.

Rowena Juan, a medical clerk, schedules and registers patients for the Strong Heart Study. She has worked for NIH for 15 years. Her career "dream" is to be a dental assistant.

Oreen Johns, Helen Johns, Joy Jones, Angie Barley, and Matilda Johns, who have worked for NIH for many years as medical clerks, recruit and drive for the Strong Heart Study. Oreen has 8 children, 10 grandchildren and 1 great grand child. Her hobbies include reading, sight seeing, walking, sewing and teaching crafts to children. She wishes to start a small craft business. Helen has 3 children and likes to bake, sew, and volunteer for the Casa Blanca "Gathering Committee". Her career goal is to become a nurse. Mother of 6 children, Joy enjoys cooking, bowling, and Indian Dancing. She hopes to work in the

computer science field some day. Angie loves to read during her free time. Her career goal is to continue to do exactly what she is doing. With 7 children and 10 grandchildren, Matilda is active at her church and enjoys gardening. Her career "dream" is to be a nurse.

Linda Phillips, the laboratory supervisor, has worked for NIH for 17 years. Linda and her assistants, Jill Loebel, Leigh Shovestull, Julie Park, and Don Warne (a pre-med student), helped the Study by drawing blood and processing the specimens for shipping.

Except the laboratory personnel, all of the above NIH Staff are residents and members of the GRIC.

Consultation for the examination is provided upon request by the physicians on site: Drs. William Knowler, David Pettitt, Mohammed Saad, Robert Nelson, and Aline Charles.

Others who assisted on the Strong Heart Study include: two summer students, Allison Drash and Veronica Williams; and two master's students, Greg Wood and Daryl Allis.

The following individuals also contribute to the Strong Heart Study at the GRIC: Viola Johnson, Sacaton Service Unit Director, Dr. George Ting, Medical Director, Dianna Garcia-Smith, PHN Supervisor, and JoAnne Hurley, Dietician.

#### STRONG HEART STUDY PARTICIPANT IN SEVERE CONGESTIVE HEART FAILURE REFERRED FOR EMERGENCY CARE

A 61-year-old man from Allen, South Dakota came into Kyle Clinic against his better judgement at the insistence of his daughters and wife to participate in the Strong Heart Study on May 8, 1990. He had not seen a health care provider since 1979. His wife had been encouraging him to come in for the past month because he had not been feeling well, but he had refused to come. He had an episode of severe chest pain lasting over 30 minutes two days previous to exam and cough for one week. He had been unable to sleep lying down for over a week, so he was only getting a couple hours of sleep a night sitting up in a chair. He had chest, pains on and off for a month. His wife stated that his heart was pounding so hard four nights prior to the exam that the bed was shaking.

Dianne Rand, RN, FNP, examined his heart and found an irregular heart beat (atrial fibrillation) and abnormal cardiogram. He had severe signs of congestive heart failure (CHF).

Ms. Rand quickly arranged transportation by ambulance with oxygen running to Pine Ridge Hospital. The patient was admitted for treatment of CHF and to rule out a heart attack. From there he was transferred to the VA Hospital in Hot Springs where he was treated for his atrial fibrillation and his CHF. He improved with treatment and was discharged home on May 15, 1990, very grateful to the Strong Heart Study staff and his physicians for making him feel better.