



# STRONG HEART STUDY NEWSLETTER

INVESTIGATING DISEASE IN AMERICAN INDIANS

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## Strong Heart Investigators Meet with NIH ...American Indian Health needs discussed

Three American Indian physicians, who are currently active researchers with the Strong Heart Study, were among the presenters at a meeting sponsored by the National Institute of General Medical Sciences and the Indian Health Service. Yvonne Roubideaux, current President of the Association of American Indian Physicians and affiliate with the Arizona Center, was Chair of the meeting. Jeff Henderson, co-investigator with the South Dakota Center, and Dorrie Rhoades, affiliate with the Oklahoma Center, were invited speakers in the gathering which addressed the research training needs of American Indians.

Representatives of academia, tribal governments, American Indian-focused associations, and American Indian students gathered at the National Institutes of Health (NIH) to comment on training needs. After initial presentations by speakers from each of these groups, the participants broke into working groups to generate recommendations to NIH in four areas: 1) issues of credibility and trust with the American Indian community, 2) needs of basic science investigators, 3) needs of MD/professionals who want to do research, and 4) means of engaging/encouraging students to seek research careers.

Representatives of the various institutes within NIH were invited to observe. Richard Fabsitz, Project Officer for the Strong Heart Study, represented the National Heart, Lung and Blood Institute at the meeting. Observers from the NIH were specifically excluded from

the deliberations of the working groups that were formed around each of the four topics. Under this format, the recommendations were truly advisory from the community that is being served. After meeting and formulating recommendations, the working groups presented their ideas for final discussion and comment by the participants and observers. A formal report incorporating the final recommendations will be published in the next few months.

The experiences of the Strong Heart Study contributed in many ways to the discussion at this meeting. Clearly, each of our young American Indian investigators from the Strong Heart Study played a significant role in the deliberations of this committee. We look forward to receiving the recommendations of this group regarding meeting the research training needs of American Indians.



From left, Richard Fabsitz Project Officer of SHS, Drs. Dorrie Rhoades, Jeff Henderson, and Yvette Roubideaux

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# Prevention and Family Study Programs

require research dollars

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## SHS Seeks Funds

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**W**hether a study is new, has been piloted, or has finished one phase and needs to begin the next phase, funding is required. Research dollars are available through grants, but receiving grants requires writing proposals for evaluation. Even after proposals are written and submitted, they may not be funded. The

Strong Heart Steering Committee is working with new, piloted, and previously done projects that all have funding requirements.

A prevention strategy program is a new study idea in the first stages of the funding process. Believing that learning how to prevent heart disease is crucial, the Strong Heart Steering Committee asked and received permission from tribal leaders to request funds from the National Heart Lung and Blood Institute (NHLBI) of the National Institutes of Health (NIH) to be part of a nation-wide study of the prevention of cardiovascular disease. The committee prepared a lengthy, detailed proposal and answered subse-

quent NIH questions, but the proposal was turned down. Tribal leaders as well as community and Strong Heart Study committee members were very disappointed but still believed that a research study should be conducted and decided to continue their funding attempts. When Drs. Barbara Howard and Jeff Henderson met with the

now needs funds to expand. The pilot showed NHLBI that SHS is capable of doing a larger family study and more importantly, that the communities in Arizona, the Dakotas and Oklahoma support doing a Family Study. In October 1999, the SHS Steering Committee submitted a proposal to continue the study. If funded, the research will

study whether risk factors in families are inherited. The study would also provide the first information on risk factors in younger American Indians and will answer questions about when young people start to show signs of heart disease.

With funding for the above studies still being sought, the SHS

received good news in the form of a request to repeat the sleep studies and the funds to do so. The original participants of the Sleep Heart Health Study will be asked to take part in the next phase which will probably begin in November 2000.

Tribal officials and community leaders are also an important part of funding efforts. Their support letters are greatly appreciated.

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### SHS Programs/Funding

prevention strategies

*writing proposal*

risk factors in families

*proposal submitted*

Sleep Studies

*funded*

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director of NHLBI in Washington, D.C., he encouraged them to submit a new prevention study application for research to meet the specific needs of SHS communities. The committee is working to meet the June 2000 deadline.

The Strong Heart Family Study, originally a small pilot or feasibility study done as part of the recently completed Phase III of SHS,

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# Genetics:

## Questions Answered

### What studying genetics may mean to American Indian Health

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**Y**ou have been hearing a lot in the news about genetics. A preliminary family study to look for the effects of genetics on cardiovascular disease was a part of the recently completed Phase III of SHS and this will be expanded in Phase IV to include more family members. This is the first of a short series of articles about what genetics is, how we study it, what it might mean to American Indian people....both the positive and negative aspects of this kind of research.

Medical researchers study differences to learn about how our bodies work and how disease happens. Ever since the first grandmother thousands of years ago noticed a cough, a runny nose, or felt a forehead for fever, we have looked for differences and tried to discover connections that allow us to understand, predict and treat disease. Our ability to find differences keeps getting better; now endoscopes look inside the body, MRI and ultrasound generate pictures of organs at work, and other complicated equipment is used to detect and measure important differences. We have found other important differences besides those between individuals. Environmental differences (insects, toxins, habits, diet) can have important effects on health. Some families have genes that cause problems like high cholesterol, bones that break easily, and mental retardation. Some racial and ethnic differences make certain diseases such as sickle cell anemia, cystic fibrosis, Tay-Sachs disease more likely. At first glance most of these differences seem to have negative influences, but as we will see in later articles, it is usually not a simple case of positive or negative.

Genetic testing is the latest means of finding differences that we hope to use in better understanding the reasons for disease.

Sometimes when we talk about genetic problems, we get a little discouraged. We say we can do something about our blood pressure or our cholesterol, but we can't change our genes! Well, it is true that our genes can't be changed (yet), but there are things that we can do about these problems. About 60 years ago it was discovered that some persons with mental retardation had high levels of a particular amino acid in their blood; and for at least the last 30 years all newborn infants (in the developed world) are tested for what is called PKU. This genetic condition is caused by a problem with a single gene that processes this amino acid. Following a proper diet allows these individuals to achieve perfectly normal intelligence and live normal lives. So in this case a very serious genetic problem can be overcome in a rather simple way by altering our environment. When you think about the controversy that DNA testing often generates, it is amazing that this form of genetic testing (although it doesn't directly test the DNA) is mandated by law and that informed consent of the parents is almost never required....yet most people have accepted this form of testing without much controversy.

Why have genetic researchers often been so interested in studying American Indian people? As mentioned in the beginning, differences between people help us to understand nature. The differences in genes and the likelihood of diseases in different groups of people present an opportunity to learn about the causes of disease and health. In many ethnic groups, certain families with genetic conditions have been very helpful in figuring out the basic mechanisms underlying diseases. Studies in ethnic groups simplify the analysis of genetic information because we can assume that people of an ethnic group are more likely to share certain genes than people from different ethnic groups. Other advantages for researchers are that American Indian populations generally have more organized and standardized medical care than most other Americans, and on average, they have larger families. Other ethnic groups with these characteristics have used them to their advantage.

In future issues we hope you will enjoy learning more about DNA and genetics and also become interested in the other important and serious issues involved with genetic testing.

# Third Exam of Strong Heart Study Completed at all centers

The Strong Heart Study staff completed the third exams of study participants in a flurry. More than 3000 exams from the original 4549 people who agreed ten years ago to participate in the Strong Heart Study were completed at the three centers. We take heart in the large turnout and continuing cooperation of the communities that have been so supportive of SHS since it began. We are saddened that many of the original group are no longer with us.

We all share the commitment to make the most of the data gathered from this study to learn more about the causes of disease and potential opportunities to reduce the burden of disease for the members of these communities and their future generations. While the exams are now complete for this study, we will continue to contact participants periodically to determine their health status. In addition, some members of the original group may be asked to participate in an expanded Family Study. This expanded Family Study is still in the planning stage and will require funding approval from the National Institutes of Health before it can begin. An application has been submitted proposing this expanded

Family Study, which will have a wide age range in order to include younger participants as well.

We want to recognize and thank the participants of the Strong Heart Study who have given so generously and willingly of their time to participate in this study. Without your participation there would be no Strong Heart Study. We also want to recognize the SHS staff; they have worked very hard going above and beyond the call of duty to make this study the best it could be. Because of that effort, we are now positioned better to understand the health risks facing American Indians in their daily lives and to begin to do something to reduce those risks.

## STRONG HEART CENTERS THIRD EXAMINATIONS

center	# of exams	% of those still living
Arizona	1028	90.6
Oklahoma	1067	84.1
Dakota	1105	90.6

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