



Strong Heart Study Newsletter

Investigating Cardiovascular Disease in American Indians

Updates for Community Members and Strong Heart Study Participants

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CONVENING ON NATIVE AMERICAN WOMEN'S HEART HEALTH

Strong Heart Study researchers and participants attended the *Convening on Native American Women's Heart Health* in December 2018. The meeting was held at the Smithsonian Institution's National Museum of the American Indian in Washington, D.C. Participants learned about heart disease among American Indian women and discussed approaches for preventing heart disease. Linda Poolaw, a Kiowa member and Delaware tribal leader, was an invited speaker. She told of her work as a tribal liaison and recruiter for the Strong Heart Study for 22 years in Oklahoma. She also spoke about her story of living with heart disease. Participants talked about the importance of women for the health of the family and community.



Linda Poolaw, Kiowa member and a Delaware tribal leader. Photo courtesy of WomenHeart.

At this same meeting, Dr. Richard Devereux, Director of the Cardiovascular Center for the Strong Heart Study from Weill Medical College of Cornell University, talked about Strong Heart Study findings over the last 25 years. Cardiovascular disease incidence, or risk of disease, is declining. When comparing people at the same age, for example when they were 45, Strong Heart Study participants born in more recent generations have a lower risk of heart disease. Risk of death declined more for men than women, but presence of heart disease declined more for women. These findings are from the paper written by Dr. Clemma Muller, Dr. Devereux, and other Strong Heart Study Investigators.



Richard Devereux, MD, Professor of Medicine, Weill Cornell Medical College, Strong Heart Study Cardiovascular Center



Clemma Muller, PhD, Assistant Research Professor in the College of Nursing at Washington State University

SPECIAL DIABETES PROGRAM FOR INDIANS CHANGING LIVES ON THE SPIRIT LAKE RESERVATION THROUGH THE “SACRED LIFE CENTER”

Tracy Charboneau has a very exciting story that needs to be shared. She is a woman who greets everyone she meets with a smile, and asks them how they are doing. People respond naturally to her and are happy to see her as well. Tracy began her career by going to nursing school in Grand Forks, ND at UND. While she was there, she experienced an event that scared her. She describes the symptoms of loss of vision, extreme thirst, and tired feeling. In a whirlwind, she ended up receiving insulin for a blood sugar level that was considered extremely high. The diagnosis of Type 1 diabetes frightened her, and at the time it was happening, she felt like she was dying. Medical staff reassured her that it wasn't that extreme. Fast forward one year later, and she was finishing her nursing degree. Through a passing conversation, she reached out to Peggy Cavanaugh, the Spirit Lake Health Director, and asked if there were any available positions. It just so happened that they were hiring for a registered nurse for their Special Diabetes Program for Indians (SDPI). For Tracy, it felt like everything was falling into place: her new job would help her to be able to connect with people who were going through a diabetes diagnosis and to educate them about what they could do for their diagnosis.

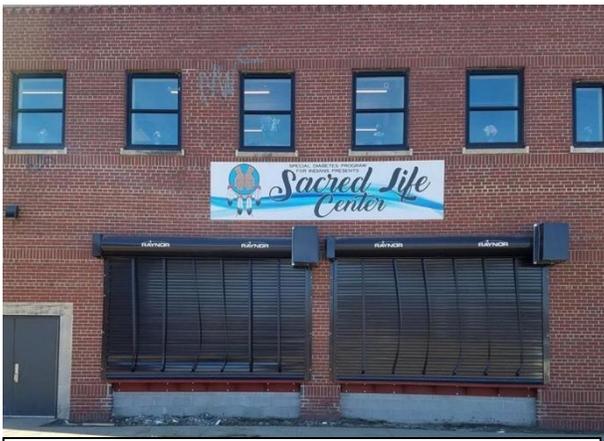
The Special Diabetes Program for Indians began in 1997 when the United States Congress authorized \$150 million annual funding towards Diabetes Prevention and Healthy Heart Initiatives and the Community-Directed Diabetes Programs to be used by Indian Health Service, tribal and urban Indian health programs. The funding came about as a result of a report by the Strong Heart Study that suggested that the risk for Cardiovascular Disease in American Indian adults with diabetes may be 3 – 8 times higher than those without diabetes (Diabetes Care, 2003). Diabetes was 2.3 times more likely to be diagnosed within American Indian community member compared to non-Hispanic white people. Complications beyond CVD included increased rates of kidney failure, stroke, and overall increased rate of deaths a result of diabetes. Additionally, people who have diabetes have higher overall medical costs. (Indian Health Service, 2012)

The Strong Heart Study began in 1988. It was a result of the National Heart Lung & Blood Institute doing a Request For Proposals following a committee commissioned by the Secretary of Health and Human Services Task Force on Minority Health determination that inadequate information was available on cardiovascular diseases the American Indian populations. It was the beginning of the largest epidemiological study in Indian Country up to today, and consists of diverse American Indian populations from the Dakotas, Oklahoma and Arizona regions.

Fast forward to 2016, Tracy Charboneau, MSN and her counterpart, Challsey Scallon, MSN, were nurses working on



Tracy Charboneau, MSN and Challsey Scallon, MSN



Sacred Life Fitness Center, Spirit Lake Reservation

the Spirit Lake Reservation in the Special Diabetes Program. The determination was made that the additional monies available within their SDPI budget needed to be used. In the beginning, they began exploring different avenues to open fitness centers that would be accessible to their community members over a diverse land area. Initially, they started with the idea of modular buildings, and experienced road blocks. The next building they looked at for a Fitness Center burned down. Some people may have felt that the challenges were not to be overcome, and yet when a community member named Mary Cavanaugh, a former planner, approached them with the idea of renovating an old bus garage, they kept an open mind. Tracy stated "right away, the first time we went there, we knew that this would be where the

fitness center would go, it just had a really good feeling." Over the next months, Tracy and Challsey worked to bring the vision of a fitness center to Spirit Lake to life. They planned, designed, and implanted their vision: a Barriers-Free Fitness Center that every person would be welcome at. "In the beginning, we thought it would be great if there was a place for people who had diabetes to meet at. Then our visions got even bigger: what if we could prevent diabetes, and all the other chronic illnesses that go along with it?" Tracy lights up as she explains the many different ideas that their program utilized to get people to the fitness center, and to decrease their barriers. "We even thought, what if 100 people were using this facility? I believe that the last time that I checked there were over 800 members enrolled at the facility, with an average of 30 to 40 people per day using it." The Fitness Center had its 2nd Anniversary in March 2019. The Fitness Center staff is continually working to find new ways to bring programs and decrease barriers for people on Spirit Lake. Incentives have been utilized such as providing tickets for people to use transit and providing gas card vouchers for people who were driving. Success stories include people with diabetes who received focused health education plans for themselves that led to changes in their lives, families who come to work out at the fitness center together and youth who bring friends and family to the fitness center as they transform their lives.

When Tracy describes the changes that the Sacred Life Fitness Center has made on the Spirit Lake Reservation, it is clear that a positive impact has been made for many. "There's a lot of healthier choices being made. There's people in the community that started their own weight loss challenges. They have walking clubs. I really do think that it made an impact, and that's the most important thing to me, we want to make an impact, we want to see changes. A lot of people think like "well, when I get diabetes..." they think that it's an automatic; they think you



Exercise Equipment at Sacred Life Fitness Center, Spirit Lake Reservation

have to get it. We started teaching people that you don't have to get diabetes; you don't have to have all these other comorbidities and stuff. With small changes in your lifestyle, it can really make a difference." As Tracy elaborates "I think it [research] is a wonderful thing because it teaches us. Everything we do now with Special Diabetes is all evidence-based practice. I think it's a wonderful thing because it's actual evidence of what you can do to prevent or what you can do to manage, so I think it's really great."

Story written by Marie Gross, RN, MPH of the Dakotas Field Center

“I WANT MY PEOPLE TO HAVE A BETTER LIFE.”

- MARIE RANDALL

I met with Marie Randall on a day in mid-May. The Dakota prairie winds are quiet, the grass green and the temperature a beautiful 70 degrees. It was to be an omen of the woman inside. It is hard to just come up with one word to describe this tiny powerhouse but the words grace, humility, determination, commitment, warrior all come to mind. At 99 years of age, Marie Randall is a force to be reckoned with. For this woman, life has been and continues to be about her family, her community and her people. She is Lakota. And she exemplifies all that each of us should attempt to become in our lives.

Surrounded by a busy household in which family members and neighbors come and go, I sat down with Marie to visit about her years of participation in the Strong Heart Study. I wanted to know why, what motivated her all these years to participate. What was her hope for the study, what did she expect would happen as a result of her participation?

For Marie her reasoning is very simple. She wants health for her community members. As one of the first Community Health Representatives (CHR) in the area, she has led by example. She recounted the story of her and several other women – Peggy Two Crow and Ellen Moves Camp, leaving their homes to go to CHR training in Arizona for 6 weeks, and then coming home where she worked in her community as a CHR for 32 years. She recalled meeting with Robert Kennedy to discuss her community’s need to have a medical clinic. The closest hospital was 100 winding miles away and if the patient needed a specialist it was another 100 miles farther. She smiled when she told of how the clinic was only opened on Thursdays, “Folks could only be sick one day a week”.

Marie talked about the changes that have come to health and health care for her community. As a fluent Lakota speaker she remembers helping doctors to speak with her community members about new treatments for tuberculosis (TB) and educating her community members about diabetes. “We lost a lot of people through illness, today they can make an appointment and get treatment. Today they have something called a stent, people have a heart attack and they go to Rapid City and then they come back and they are just like everyone else. They know how to eat differently and how to exercise. They thought that I had a heart attack and they transported me to Rapid City and ran all kinds of tests. The doctors told me that I was okay but they sent me home on a pill and an aspirin. Today that is all that I take”.

What did she think about the samples and data that were given for the tests that were run? She said that she envied today’s medical people as we used to have to use a dip stick to test urine for high sugar and now they



Marie Randall, Lakota, 99 years old

have much better tests. Now they don't have to shake down the thermometer, they just swipe an instrument across their forehead and they are done. At 99 Marie is full of hope for the promise of innovations that have come to improve health and at 99 Marie plans to continue to be a part of and promote critical research that can help her people.

"We do this for those people coming behind us, for the children. They should store those samples so that they can fall back on it to learn more about the changes over generations and use it to treat the younger generations. Anything that we want to develop, there is a cost to it. Today there are instruments that can test these samples to help understand what was not available before."

"I want my people to have a better life."

Story written by Marcia O'Leary, RN, Manager of the Dakotas Field Center



STRONG HEART STUDY STORED SAMPLES

Stored samples that were collected from Strong Heart Study participants continue to be used to answer important health questions. Biologic samples from Strong Heart Study participants are stored at two locations. Plasma, serum, urine and DNA samples of participants in the Strong Heart Study, and plasma, serum and urine samples of participants of the Strong Heart Family Study are stored at the MedStar Health Research Institute in Bethesda, Maryland. DNA samples and white blood cells from the Strong Heart Family Study are stored at the Texas Biomedical Research Institute in San Antonio, Texas. Specimens are sent to approved researchers to answer cardiovascular disease questions.

Researchers must submit their research project plans to the Strong Heart Study Steering Committee for review. Tribal health boards, Indian Health Service, and university or institutional review boards also review the projects to decide if the study asks a question that is important to Strong Heart Study communities using strong scientific methods. Projects are only approved if they study cardiovascular disease and risk factors as described in the study consent forms that participants signed. Samples can only be used for the approved studies by the approved researcher, and researchers must return unused samples in good condition to the Strong Heart Study storage locations.

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NEW PROGRAMS - PHASE VII

The next phase of the Strong Heart Study, Phase VII, has been funded by the National Heart, Lung and Blood Institute of the National Institutes of Health. Phase VII will last from February 2019 through February 2026. The project will provide funding for follow up of cardiovascular and other health conditions, as approved by tribes, among Strong Heart Study and Strong Heart Family Study participants. It will also provide support for new studies focused on health areas of interest to tribal communities, including heart health, diabetes, nutrition, physical activity, stroke, cancer, disease prevention, and other areas. New programs will be funded including community-based pilot projects. There will more opportunities for community education and training in addition to ongoing training of American Indian students, health professionals and researchers. **Thank you for your participation and support of the Strong Heart Study!** Without your commitment this study would not be possible. We look forward to our continued collaboration and work to improve the health of American Indian communities.

Please visit the
Strong Heart Study Website!
<http://strongheartstudy.org/>
We welcome your suggestions and
feedback!