



***“Providing Clinical Genetic Services
in American Indian Communities”***

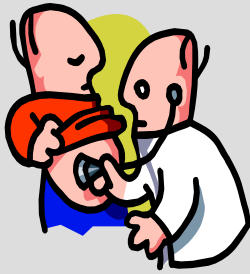
***Bismarck, North Dakota
8/26/11***

A LITTLE ABOUT ME

- GREW UP AND GRADUATED FROM HIGH SCHOOL IN WAHPETON, NORTH DAKOTA
- BACHELOR’S DEGREE IN CHEMISTRY, UND, 1970
- MD, A. EINSTEIN NEW YORK, 1974
- FAMILY MEDICINE RESIDENCY, NORTH MEMORIAL, MPLS, 1977



LATER



- FAMILY DOCTOR WITH IHS 77-98
- DELIVERED BABIES, MI's, BROKEN BONES, CAR ACCIDENTS, ETC
- AREA MATERNAL-CHILD HEALTH CONSULTANT, 1994-98
- PART TIME PRACTICE, JOHNSON CLINIC, DUNSEITH, ND, 1999 TO PRESENT
- TEACH FAMILY PRACTICE RESIDENTS, MINOT, 1990 TO PRESENT

TEACHING/RESEARCH



- REPORTED ON CERTAIN GENETIC CONDITIONS AMONG AMERICAN INDIAN COMMUNITIES WHILE WORKING WITH IHS
- BEGAN WORK WITH STRONG HEART STUDY IN 1998
- DNA DIAGNOSTICS LAB, WINNIPEG, CA, 1998-1999
- TAUGHT "INTRO TO GENETICS" AT TURTLE MOUNTAIN COMMUNITY COLLEGE SINCE 1999
- INITIATED "GENETICS AND PRE-ECLAMPSIA STUDY" AT TMCC, 2004

GENETIC RESEARCH AS A TEACHING MODEL



STUDENT RESEARCHERS



- OBTAIN INFORMED CONSENT FROM PARTICIPANTS
- COLLECT SAMPLES, ANALYZE DNA
- RESEARCH LITERATURE, WRITE PAPER
- TEACH OTHER STUDENTS ABOUT THEIR EXPERIENCE

PROJECT STAFF

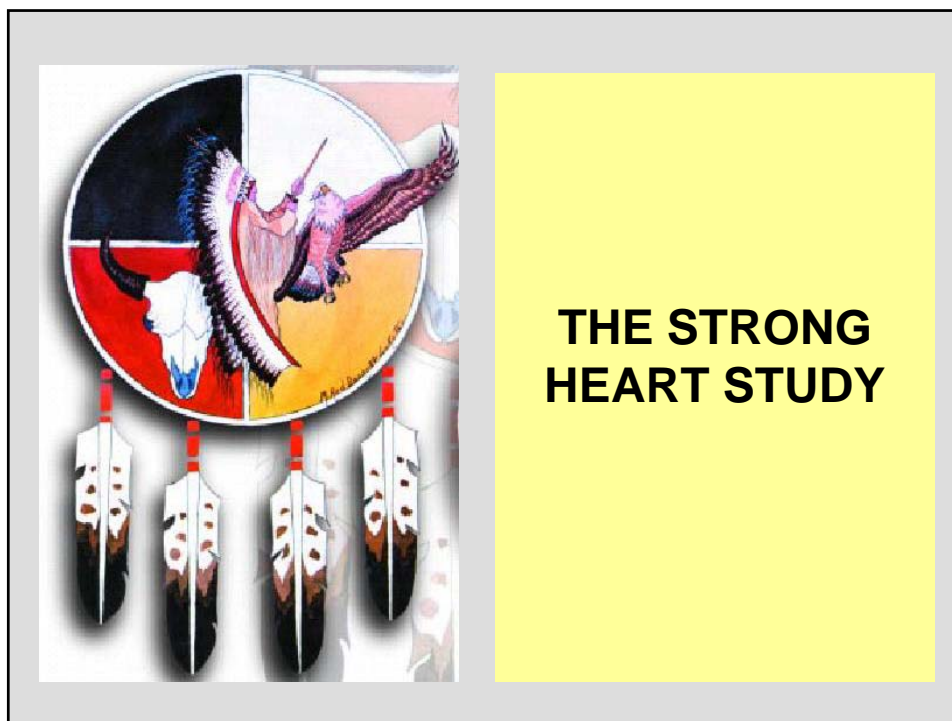


- **Melanie Nadeau, MPH**
 - Hired as Research Technician, 2004
 - BS in Psychology
 - Experienced Telemarketer
- Began Univ. Minnesota MPH program 2008
- Completed MPH 2010
- Currently PhD Epidemiology graduate student at U/Minn

Nadeau M, Best L. Recruiting American Indian women for a genetic epidemiology study. *Public Health Genomics*. 2010;13(7-8):389-95.

TRANSLATIONAL EFFORTS





Strong Heart Study

Original cohort

- Recruited 1988
- 4549 American Indians ages 45-74 years
- DNA sampled

Family Study

- Began in 2000
- Additional 3600 recruited
- Large kindreds
- Genome-wide linkage



COMMUNITY ENGAGEMENT



Marcia O'Leary, Tom Welty, Francis Ashley (SHS participant), Lyle Best

STRONG HEART STUDY OUTREACH

Genetics and You

What are genes and why are they important?

Your body is made up of tiny cells, and inside each one is a copy of your DNA. The DNA gives instructions to the cell and, more, tells it how to build and how to work. For example, the DNA inside of a skin cell determines the size of the cell, the function of the cell, and ultimately, the color of the skin. The DNA is divided up into chromosomes. The body has a set of chromosomes. On the chromosomes are "genes." You inherit your genes from your parents. Half of your genes come from your dad and the other half come from your mom. Each human's genes are very similar, with less than one of a gene being different from one another. However, that small difference makes each one of us unique.

Genes determine how a body builds and acts. The body is like a machine and a gene is like a part of the machine. Some genes tell the body how to build a part of the machine. Some genes tell the body how to get certain diseases. For example, a gene might tell a person how to get heart disease because he or she has certain forms of genes in his or her body.

The good news is that your environment (where you live, how you spend your time, what you eat, etc.) can change the way your genes give instructions to your body. For example, if you eat healthfully and exercise regularly, you might be able to avoid having heart problems, even if both of your parents have heart problems.

Heart Disease, Genes, and American Indians

Scientists discovered that American Indians living today appear to be more likely to get heart disease than other groups of people. Learning about the genes of American Indians will help us determine why American Indians are more likely to get heart disease than other people are. Scientists are looking at particular genes on the chromosome, and the CHS has found some genes on certain chromosomes that affect risk factors for heart disease (see image on the right). We hope our future research will lead to ways to prevent the most genes affecting your risk of heart disease and how the environment can change the way the genes tell the body to work. For example, a certain form of a gene might make a person more likely to get heart disease, but one of the genes also makes cigarettes or has a particular diet.

Understanding how genes and the environment affect American Indians can improve your health and quality of life.

Genetic Risk Factors for Heart Disease: Some Results from the Strong Heart Family Study

- ▶ This region may increase or decrease how fast your heart beats.
- ▶ Change in this region may affect the size of the left heart chamber (left ventricular mass).
- ▶ These regions carry information that may affect blood pressure.
- ▶ These regions carry information that may affect how well a person's kidneys are functioning.
- ▶ Change in these regions may affect a person's risk for diabetes.

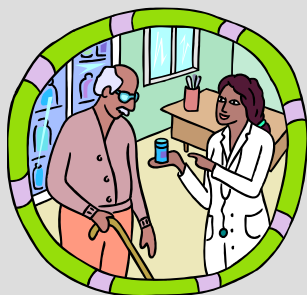
- NEWSLETTERS
- COMMUNITY MEETINGS
- RADIO PROGRAMS
- NEWSPAPER ARTICLES
- PRESENTATIONS TO OVER 20 SCHOOLS ABOUT RESEARCH METHODS AND CAREERS
- PUBLICATION REVIEW AT TRIBAL COLLEGE

PHARMACOGENETICS



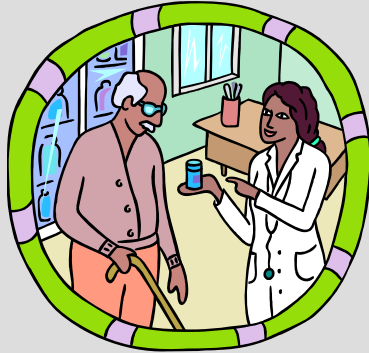
- Dr. Julie Oestreich at Univ of Nebraska
- Study of genetic influences on responsiveness to clopidogrel
- ~100 participants on clopidogrel, or controls
- Platelet aggregation measures
- Genotyping at Turtle Mountain Community College, Belcourt, ND

CLINICAL GENETIC SERVICES



- Difficulties:
 - Poor general understanding of genetics
 - General clinical services overwhelmed with urgent/chronic problems
 - Poor general medical provider appreciation for utility of genetics
 - Inflexibility of Indian Health Service contracting regulations
 - Historic/cultural concerns about genetics
 - Genetic determinism
 - Geography

CLINICAL GENETIC SERVICES



- **Recommendations:**
 - Be patient
 - Work to improve general understanding of genetics
 - Schools
 - Community meetings
 - Clinical staff
 - Be available
 - Offer informal/phone consults
 - Offer onsite/formal consultation if desired
 - Consider contracting with tribes, rather than IHS