

Healthy Signs

November 2010

Mission of NCDHR:

To promote health and prevent disease in the Deaf and hard of hearing populations through community-based participatory research.

National Center for Deaf Health Research

This Issue's Topics

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Did you know?

44,241 unique visitors have viewed the NCDHR website since it was launched in 2008:

71% of the visitors were from 50 States of America.

21% of the visitors were from 148 countries...

... the top 10 countries were:

1. South Korea
2. Canada
3. Russia
4. England
5. India
6. China
7. Spain
8. Japan
9. Australia
10. Germany

(8% of the visitors had unknown originations)

Staffing Changes at NCDHR

NCDHR is a rarity within the Prevention Research Centers (PRC) Program: its principal investigator (PI) is also the PI for the University of Rochester Clinical and Translational Science Institute (CTSI), part of a nationwide program sponsored by the National Institutes of Health.

The goal of CTSI is to coordinate an astounding number of resources within the scientific, educational and regulatory fields to shorten the amount of time it takes for scientific discoveries to develop into useful tools to improve human health in clinical practice and in the community. It is not unusual for a new medical breakthrough to take 10 years to become common practice. The CTSI aims to shorten this time substantially.

The \$76.4 million, 4-story, 200,000 square foot Clinical and Translational Science Building (CTSB), opening in April 2011, will be the permanent home of many important clinical research programs, including NCDHR.



Since the establishment of NCDHR in 2004, **Thomas Fogg, MS MPH**, has served as its part-time administrator while managing the CTSI, which received funding in 2006. Effective January 1, 2011, Mr. Fogg will give up his NCDHR responsibilities to focus on the CTSI. "Both the

NCDHR and the CTSI have grown tremendously over the last few years, and managing the two organizations is becoming more and more complicated. I love the NCDHR and I love working with all the people involved. However, it's just not possible to do justice to my NCDHR responsibilities given my growing involvement with the CTSI and related programs."

At the same time, **Erika Sutter, MPH**, Senior Health Project Coordinator (HPC) will assume responsibility for NCDHR administration. Erika has a long history with NCDHR. In 2004, she began working part-time for NCDHR as a research coordinator in the Department of Pediatrics. She became a full-time HPC at NCDHR in October 2009. Before coming to Rochester in 2004, she worked at Mt. Sinai Adolescent Health Center in New York City, while completing her Masters in Public Health at Hunter College. She is presently learning (and practicing) American Sign Language.

Erika commented that "NCDHR has grown considerably and has become more complex. I am looking forward to meeting its challenges and broadening our opportunities!"

Opportunities to "Experience" Research at NCDHR



As a Deaf pre-med and psychology student at RIT, **Tiffany Panko, BS, MBA**, has always been interested in the health-related field. But this field is so broad that it can be quite challenging to narrow down a particular field for study or a career.

A Google search for health fields yielded nearly

180 distinct health professions!

NCDHR, while primarily a health disparity research center, offers outstanding educational-career opportunities for interested Deaf and hearing students, including Tiffany. She is working at NCDHR part-time in a variety of projects, such as adaptation of the Deaf Weight Wise curriculum, conducting focus group sessions, transcribing video-based ASL to written English for qualitative data

analyzes, and working with Deaf physicians in their research projects. She also was involved in the development of video-based health education clips translated in ASL.

"The experience here at NCDHR has been so invaluable" commented Tiffany. "It gave me insights and directions as to what I am seeking for my long-term career goal. I plan to enter the clinical field."

New Deaf Healthcare Survey Coming Soon!

Another survey, called Deaf Healthcare Survey, is coming soon! This survey is Dr. Steven Barnett's K08 project from the Agency for Healthcare Research and Quality. The K08 grant is also known as the Mentored Clinical Scientist Research Career Development Award. His project involves adapting the national Consumer Assessment of Healthcare Providers and Systems (CAHPS®) to American Sign Language (ASL). More than 400,000 people take CAHPS® survey every year in the USA, in written English and other languages, to report and evaluate their healthcare experiences.

The goal the Deaf Healthcare Survey is to make CAHPS® accessible to Deaf ASL users and it focuses on the healthcare experiences of Deaf adults such as where people usually go for care, how people communicate with healthcare providers, and how satisfied people are with healthcare services. The survey data will help deaf and hearing researchers and Deaf

community leaders to identify priority areas for improvement in healthcare. The Deaf Healthcare Survey is confidential and will not collect any names. The ASL survey is "user-friendly." No computer skills will be needed to complete the survey on a touch-screen kiosk (see picture below).



Most of the standardized CAHPS® questions have been adapted to ASL by NCDHR's Translation Workgroup (TWG). The TWG consists a team of ASL fluent hearing researchers and Deaf experts from NCDHR's community partner, Deaf Health Community Committee. There also is a Signed English Workgroup. For example, a common CAHPS® question,

"Is this the doctor you usually see if you need a check-up, want advice about a health problem, or get sick or hurt?" is translated into a signing video. All survey questions and answers will be shown in ASL or English-based signing through videos and captions, if desired.

This survey is different from the Deaf Health Survey in 2008, which focused on health status and risk behaviors from the survey takers. This survey was adapted from the national Behavioral Risk Factor Surveillance System (BRFSS) which collects health data from 350,000 adults by telephone. This data, along with other health statistics, helped public health officials to find ways to improve health of Americans.

The University of Rochester's Research Subjects Review Board, an Institutional Review Board, is now reviewing the Deaf Healthcare Survey's protocol. Once approved, we will be seeking 300 deaf adults, age 18 and older, to take this survey.

What is a "Randomized Controlled Trial" ? Matthew Starr, MPH

The Deaf Weight Wise (DWW) Study Project, to be launched in summer 2011, is actually a "randomized controlled trial (RCT). RCT is a research study to find out if an intervention (or a treatment) works well enough to prevent, diagnose or treat a health problem. The main goal of DWW is to find out if the weight loss intervention program is effective for Deaf adults. The DWW intervention includes: group or one-on-one sessions in ASL, behavioral modification and motivation strategies, ASL videos, handouts, self-monitoring of eating and physical activities and more. There is a secondary goal to evaluate which approach is more effective: group or one-on-one (videophone) interventions.

Any RCTs require an adequate number of eligible research volunteers to participate in order to perform valid statistical tests. Health statistics and comparisons are scientifically required to confirm if an intervention or treatment under study really works. For the DWW Study Project, 216 Deaf adults, between 40 to 70 years of age, who live in the Rochester (NY) area and who are either

overweight or obese will be enrolled. After the research volunteers meet the study's eligibility requirements (for example: are they healthy enough to do some exercises?), they will be randomly assigned to one of 4 groups. Two groups will start the study right away (Phase I) for a 16-week session, either as a group or individually through a videophone. The next two groups will start the **same** study 6 months later (Phase II).

Research volunteers (participants) are assigned to one of the groups: they will not have a choice on which group to join. For example, a participant may be assigned to do one-on-one intervention even though he/she preferred to participate in a group session. It is like flipping a coin. Each participant will have a fair and equal chance of being either in the Phase I or Phase II groups. There will be no favoritism. This process of randomizing participants is a very important research method to make sure the participants in both phases are comparable. We do not want one group to be younger or healthier than the other

group. Suppose the Phase I group had a greater number of healthy participants than the Phase II group. Then, the results from the first 6 months may show greater weight loss in the Phase I group than the Phase II group because the healthier participants happen to be more physically active. This would have a misleading influence to the research question, "Did the intervention itself really work?"

Randomization prevents misleading influences and biases within a RCT study.

Results from groups 1 & 2 will be compared with groups 3 & 4 during the first six months of the study. That way, researchers can compare the results between comparable groups to see whether the weight loss intervention is successful.

Randomized controlled trials, if followed properly, are scientific strategies to allow researchers to reliably tell if the intervention was effective.