

Healthy Signs



National Center for Deaf Health Research June 2010

Mission of NCDHR:

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

Becoming A Research Volunteer: It's Your Decision

A pamphlet from the Office of Human Protections at the U.S. Department of Health & Human Services

<http://www.hhs.gov/ohrp/outreach/documents/3panelfinal.pdf>

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I want to become a Research Volunteer! Matthew Starr, MPH

Every year, about 80,000 medical and health research projects are conducted with approximately 2.3 million men and women participating as research volunteers. A research volunteer voluntarily agrees to be in a research study such as clinical trial or a survey. That may seem like a lot, but it's less than 1 percent of the total population in the United States (*U.S. News & World Report*, posted April 1, 2008).

In recent decades, new knowledge from health research has positively impacted our quality of life. For example, better early detection and treatment of a certain disease prevents it from becoming severe or fatal. Or, interventions were made enabling affected people to improve their lifestyle behaviors to reduce risk of getting chronic diseases such as diabetes.

However, there are not enough research volunteers, causing many more important health research projects to be scaled back or delayed. Become a research volunteer!

It is important to realize that joining a research study may or may not help you directly. Joining is strictly voluntary. There are

laws and regulations that make sure research volunteers are protected from being harmed by research.

The Office for Human Research Protections at the U.S. Department of Health & Human Services has produced a pamphlet, "It's *Your Decision*" (see link on left). It explains that as a research volunteer, you should know what you're getting into; ask questions; learn as much as you can and know the pros and cons. It's your decision!

The next issue of *Healthy Signs* newsletter, we will cover more about human research protections such as what is an institutional review board (IRB) and what's the purpose of an informed consent.

In the future, NCDHR will be doing additional surveys and research projects with the Deaf community. If you are interested in becoming a research volunteer for NCDHR, please contact us.

Your participation as a research volunteer will lead to new knowledge that will promote a healthy Deaf community!

National & International Visiting Professors at NCDHR



Irma Munoz-Baell, PhD, a hearing Senior Lecturer (an equivalent of an

Associate Professor) at the University of Alicante, Spain, will be staying in Rochester for a month, participating in NCDHR programs and activities. She earned her PhD in Public Health with her dissertation, "Investing in health: basis for a benchmarking study on the Spanish d/Deaf education." Irma looks forward to learning more about NCDHR's Deaf Health Research and picking up some American Sign

Language along the way!

Deb Guthmann, EdD, (hearing) Director of Pupil



Personnel Services at the California School for the Deaf in Fremont, spoke at NCDHR last

June 4 about substance abuse in the Deaf population. She has authored a number of articles and several book chapters focusing on chemical dependency and was a program director of Minnesota Chemical Dependency Program for Deaf and Hard of

Hearing Individuals.



Melanie Nakaji, PhD (Deaf) and **Georgia Sader, PhD** (hearing) from the University of California, San Diego Moores Cancer Center visited NCDHR

this month while in Rochester to conduct a focus group. They are developing an ASL glossary of oncology (cancer) words and launching an online training program to teach ASL interpreters oncology vocabulary.

NCDHR Happenings

Deirdre Schlehofer, EdD will be switching universities. She has accepted a tenure-track teaching and research position with the American Sign Language and Interpreting Education Department at the National Technical Institute for the Deaf at Rochester Institute of Technology. After 15 years as Senior Lecturer of ASL and Deaf Studies at the University of Rochester, she came to NCDHR in September of 2007. During that time, she became involved in numerous research projects and presentations, including Deaf Health Survey, Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey development, Deaf Weight Wise as well as a number of projects focusing on Deaf Perceptions on cardiovascular diseases, Women's Health and interpersonal partner violence — all of that while she successfully completed her doctoral dissertation! Her last day at NCDHR

will be June 30.

Congresswoman Louise Slaughter (NY-28), a long-time

supporter of the Deaf community, announced during a May 19, 2010 press conference in Washington, DC, the creation of a historic blue-ribbon task force charged to break down barriers for deaf and hard-of-hearing individuals wishing to study to become health care professionals. This task force consists of key members from three institutions: Gallaudet University, RIT/NTID and the NCDHR at the

NCDHR at the Rochester Deaf Festival

Both NCDHR and DHCC worked together to set up an exhibition booth during the June 5 Rochester Deaf Festival 2010.

Free Body Mass Index (BMI) screening with three electronic personal scales was provided to

America was presented by the booth volunteers as well as handouts given. The festival goers asked several questions about BMI and its risks with

Schlehofer, EdD, Scott Smith, MD, MPH, Denise Thew, PhD, Diana William (DHCC).

The weather was gorgeous (a little windy, though). Festival planners reported over 800 people registered

festival goers. BMI measures a person's weight in relation to his/her height, and it is closely associated with measures of body fat. Information about BMI and obesity in

some chronic diseases such as heart disease, stroke, type 2 diabetes, high blood pressure, and more.

NCDHR is grateful to the following persons for their help: **Tamala David, PhD, Mike McKee, MD, MPH, Val Nelson-Metlay (DHCC), Arlene Sankey (DHCC), Deirdre**

for this event.

For more pictures of the Rochester Deaf Festival, check out our website, www.urmc.edu/ncdhr and click Events on the top menu.