

Healthy Signs



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

National Center for Deaf Health Research

September 2010

Mission of NCDHR:

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

NCDHR is a proud sponsor of Rochester Deaf Awareness Week 2010 (Sept. 19 - 25)



Check out its events and activities on www.rdaw.rochesterdeafclub.com

All is welcome!

Contact Us:

NCDHR
P.O. Box 278990
Rochester, NY 14627
120 Corporate Woods
Suite 350
Rochester, NY 14623
(585) 758-7804 TTY
(866) 901-0727 VP/Voice
(585) 424-1469 FAX
www.urmc.edu/ncdhr
ncdhr@urmc.rochester.edu

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What is "Informed Consent?" Erika Sutter, MPH

Suppose you saw an advertisement saying that a team of researchers is looking for individuals to participate in a research study and you contacted them indicating that you would like to participate. You will be given an "informed consent" form to read and sign your name before enrolling into the study. What exactly is informed consent?

Informed consent provides information for an individual to decide whether he or she wants to participate in a research study. The information should be easily understood and described in that individual's preferred language. For example, the information in the informed consent form for Deaf people can be shown in written English and/or in ASL video. Information includes a full description of the research study, what are the risks (or discomforts) and benefits to the study participant, how confidentiality will be handled, and who to contact if there are questions. If the individual has questions about the research study, or is not clear about something in the informed consent, he or she can ask the researchers for clarification. The individual, after reviewing the information, then can make his or her own decision to

participate in a study, or not. The decision must be made freely - with no pressures, fear, or improper influences. If the individual decides not to participate in the research study, there will be no penalty of any kind.

Informed consent is required by federal law and it is designed to protect people interested in participating in a research study.

Sometimes individuals do not bother to ask questions because they may feel their questions are "not too smart." **There are no stupid questions!** You have a right to know everything about the research study. The individual is strongly encouraged to discuss the informed consent with family members, friends or advocates, and the researchers. Always keep a copy of the informed consent, but keep in mind that informed consent is ***not*** a contract. If the individual did agree to participate in the research study, but then decides later to drop out, again, there will be no penalty.

Also important; informed consent helps you learn more about the research study. You have a right to ask questions before, during, and after a research study. Any time!

Deaf Strong Hospital 2010

Deaf Strong Hospital (DSH) is an interactive role-play exercise for first year medical students from the University of Rochester's School of Medicine and Dentistry.

Last August 27, DSH 2010 brought over 40 Deaf community members to act as "doctors" as well as 104 medical students who were given a fictitious illness and told to go to "Deaf Strong hospital" as "patients."

Since being Deaf is the norm in this make-believe hospital, no speaking was

allowed. Instead the medical students had to communicate through finger-spelling, sign language, gestures, or write notes.

Deaf Strong Hospital was not meant to portray Strong Memorial Hospital run by Deaf health professionals. The term, "Strong Deaf" refers to a population of deaf people who are members of a linguistic minority with their cultural norms, mores, and values different than those of the majority community. Their shared language is American Sign Language.

DSH was established by a group of UR medical students in 1998. Presently, DSH is



sponsored annually by NCDHR, which meets its educational goals, along with the core Deaf Health research goals.

New Deaf Researchers at NCDHR



Poorna Kushalnagar, PhD, is the newest Preventive Cardiology Fellow at the Department of

Community and Preventive Medicine and a member of the NCDHR's Research Committee. In collaboration with NCDHR, her primary focus is on neuropsychological correlates with obesity and quality of life among deaf and hard of hearing youth.

Dr. Kushalnagar was born in India. After her parents discovered she was deaf, they moved to United States when she was one year old. Following graduation from a mainstreamed high school in Memphis, TN, she went on to earn her BA degree in Psychology from Gallaudet University.

Dr. Kushalnagar continued her education at the University of Houston, where she received a MA in Psychology (Clinical Neuropsychology Track) and PhD in Developmental Psychology with focus in Developmental Cognitive Neuroscience.

Following completion of her

doctorate, Dr. Kushalnagar was awarded a two-year Research Supplement to Promote Diversity in Health-Related Research and Pediatric Research Loan Repayment Award from the National Institutes of Health (NIH) to support her postdoctoral research training with the Department of Health Services at the University of Washington.

She and her Deaf husband have two hearing sons, ages 11 and 12, and they have traveled to many national parks in USA, Costa Rica, France, Switzerland and Hawaii. They are planning to visit South Africa next year.



Dr. Denise A. Thew, a Vancouver, BC native, received her doctorate in Psychology from the University of North Dakota. Dr. Thew is now a post-doctoral fellow with the Community and Preventive Medicine at the University of Rochester Medical Center, and a psychotherapist for the Deaf Wellness Center at Strong

Memorial Hospital. Most of her current research experiences will undertake at the NCDHR.

Dr. Thew's dissertation explored the gray areas of multiple relationships that Deaf therapists face when providing services to the Deaf community, and she developed a new ethical decision-making model that might become widely distributed for other therapists or professionals working in other smaller communities (e.g. Lesbian, Gay, Bisexual & Transgender groups, veterans, etc.). Dr. Thew's past research also included exploring the acculturation stress and resilience among Deaf individuals who work in a predominately hearing worksite.

As a post-doctoral fellow, her primary focus will be career development in scientific research and academic aptitudes. Dr. Thew's current research will focus on health disparities in the Deaf community which includes exploring effective interventions for the Deaf population.

Welcome Poorna and Denise!

External Advisory Committee (EAC)

Since NCDHR is a community-based participatory research center, its community partners play a vital role in generating better results and effective interventions, identifying community strengths and resources, improving trust and creating more career opportunities for the Deaf people.

There are five community-based partners that work with NCDHR: Deaf Health Community Committee (DHCC, meets monthly), External Advisory Committee (EAC, meets once a year), Local Partner Advisory Board (LPAB, meets quarterly) and the newly formed Hard of Hearing Health Task Force (meets quarterly).

On September 2, members of the EAC visited NCDHR for their annual meeting. They are: **Dr. T. Alan Hurwitz**, President of Gallaudet

University and Chair of EAC, **Nancy J. Bloch**, CEO of the National Association of the Deaf, **David Ebert, MD**, Medical Director of Deaf Access program in Chicago, **Ken Levinson, CPA** of San Francisco and Board Member of the Alexander Graham Bell Association for the Deaf and Hard of Hearing, **Pam Lloyd-Ogoke**, Chief of Community Services Section within the North Carolina Division of Vocational Rehabilitation, **Charles Reilly, PhD**, Senior Research Scientist at Gallaudet Research Institute (substituting for **Senda Benaisa, MPH**), **Philip Zazove, MD**, Deaf physician and Clinical Professor of Family Medicine and **Jennifer Cheng, PhD**, of the National Park Service (substituting for **Brenda Battat**, CEO of Hearing Loss Association of America). During the

EAC meeting, there was a moment of silence to remember a former EAC member, **Marcia Dugan**, who passed away after a courageous battle with leukemia.

After a full-day of productive meetings, EAC concluded with positive comments regarding NCDHR's first 5 years of research endeavors. EAC also put into motion a request for the center to look ahead its plans for the next 10 years.

