

Mission of NCDHR:

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

Healthy Signs

National Center for Deaf Health Research April 2012



The Exploratory Task Force

Tiffany Panko Accepted to Medical School

Where are they now? Ian DeAndrea-Lazarus

Open House at NTID

Community-Engaged Health Research Methods

A Visit from Uganda

What is Diversity?

Q & A Regarding Research and Diversity at NCDHR

Click on the title of the article you want to read. This will take you directly to the article! Click on Healthy Signs to take you back to the cover page.

The Exploratory Task Force (ETF) Working towards partnering with NCDHR

The ETF has been formed which parallels the original Deaf Health Task Force in 2003. The origins of the Deaf Health Task Force stemmed from research questions regarding underserved populations by the Finger Lakes Health Systems Agency (FLHSA); this Task Force later became the Deaf Health Community Committee when the University of Rochester was awarded a Prevention Research Center grant.

The ETF started with about 20 interested and carefully selected individuals from different segments of the Rochester Metropolitan area. There are about 10-12 members who have been consistently present, have maintained a focused interest and participated in monthly meetings since August 2011. Almost all of these members are also HLAA (Hearing Loss Association of America) members, active in the Rochester Chapter with leadership roles.

Of note, several members have become energized by the “accessibility factor” in that they are able to understand every word spoken and interpreted. Thanks to the NCDHR, The Pearson Family Conference Room is equipped with an FM System, C-Print (Captioning in Real Time) has been provided as well as an ASL interpreter. The installation of an Induction Loop is also being considered.

In January, Katy Stevenson from University of Rochester Medical Center, acted as facilitator to assist the committee to form mission and vision statements, and to determine our goals including areas to research.

The ETF now has identified their mission and is close to consensus on our vision statement. We are also in the process of re-naming the ETF. Several areas of research are being considered; the decision is planned to be determined by October 2012. Under consideration is the relationship between aging with hearing loss and the consequences of untreated hearing loss.

In the fall a follow-up search for additional ETF participating members will be completed to increase the committee size. The ETF is expected to become a key partner of NCDHR.

Active ETF Members are:

Don Bataille, Ann Marie Cook, Elise DePapp, Pete Fackler, David Koon, Barb Law, Larry Medwetsky, Bess Herbert, Sue Miller, Marlene Sutliff, Mary Chizuk, Chairperson



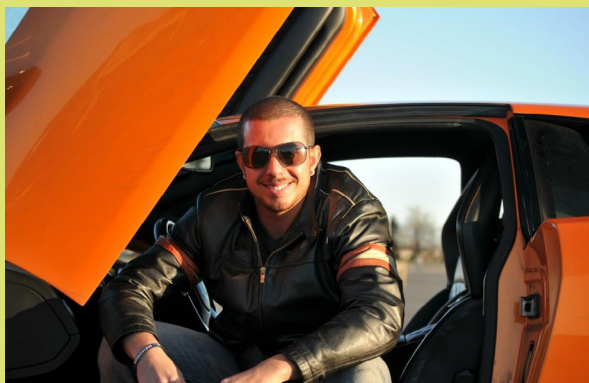
Tiffany Panko Accepted to Medical School NCDHR Wishes her a Warm Farewell

NCDHR is tremendously proud to announce that on March 23, 2012, Tiffany Panko, a Health Project Coordinator with the NCDHR, was accepted to medical school at the University of Rochester's School of Medicine and Dentistry! The extensive four-year training program to earn a professional degree as a Doctor of Medicine will start in August 2012. Tiffany is considering a career in either neurology (the medical specialty dealing with disorders of the nervous system) or endocrinology (a branch of biology and medicine dealing with the parts of the body that release hormones and the diseases that can affect those hormones).



Tiffany, an alumna from the Rochester School for the Deaf, has spent the past few years working with NCDHR. Tiffany felt that working at NCDHR has helped her prepare for medical school by "seeing public health through the eyes of the community", something Tiffany feels will benefit her in a healthcare career in her future.

This is a huge accomplishment for Tiffany Panko. When asked how she felt about entering medical school, Tiffany said, "I feel both ends of the spectrum; very excited, and very nervous! This will be like training my brain for a marathon!" NCDHR is confident that she will do great in medical school and will prove to be an invaluable member of the medical profession. NCDHR wishes Tiffany the very best of luck and hopes to see her again soon! Here's a round of "Waving Hands" for a job well done Tiffany!



Where are they now?

Ian DeAndrea-Lazarus

I am nearing the end of my first year as a post-baccalaureate fellow in the Molecular Mechanisms of Tumor Promotion section of the [Laboratory of Cancer Biology and Genetics](#) at the National Cancer Institute (NCI) in Bethesda, MD. NCI is a part of the National Institutes of Health in Bethesda, MD. My biomedical research mainly focuses on thermoregulation and pain receptors associated with cancer. My future plans consist of another year working at the lab before applying for medical school in the fall of

2013. The NCDHR summer internship helped me gain experience in a field of population-based research which is very different than the biomedical (laboratory) field I am in now. While the experience at NCI has been very rewarding, my desire to work with people (especially deaf people) as a medical doctor is now my educational and career goal.

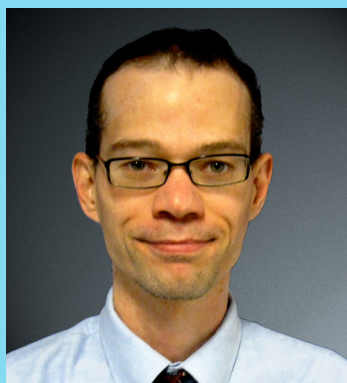
Open House at NTID

Raising Awareness and Administering Surveys

On April 23, 2012, NCDHR held an Open House at the National Technical Institute for the Deaf at RIT. The event was to raise awareness of efforts by NCDHR to promote health and prevent disease in deaf and hard of hearing populations through community-based participatory research (CBPR). NTID students, faculty and staff stopped by our tables to learn more about NCDHR. Visitors who were eligible were also able to take the Deaf Healthcare Survey. To learn more about this study, [click here](#). They were also screened to see if they were eligible for NCDHR's main research study, Deaf Weight Wise. To learn more about this study, [click here](#). A video of an ASL adaptation of a published peer-reviewed article, "Community Participatory Research with Deaf Sign Language Users to Identify Health Inequities," was also shown during the event. Open House visitors commented that they realized that NCDHR was doing vital work with the Deaf community to ensure that the Rochester ASL community will no longer be invisible in community-based healthcare initiatives. Please keep an eye on the [NCDHR website](#) for presentations and events to come as well as learn more about our research opportunities. To [view this video](#) or learn more information regarding the research studies, please click on the links provided.

Community-Engaged Health Research Methods

Scott Smith's New Class



Scott Smith, MD, MPH, a National Institute of Health (NIH) researcher and faculty with the Department of Community and Preventive Medicine, has recently started a course here at the University of Rochester's School of Medicine and Dentistry, titled "Community-Engaged Health Research Methods". Dr. Smith will be teaching the course which focuses on helping students gain a deeper understanding of relevant issues, concepts, and methods in robust community-engaged health research, utilizing case studies from NCDHR's Deaf Health research

Classes are open to the public and run Mondays from 1-4pm, May 21-July 30, 2012 in the Saunders Research Building. This is a 3 credit class.

A Visit from Uganda

Exploring Opportunities for Health Research with Deaf People in Africa

On April 2, 2012, a scientist working in Africa came to Rochester to visit NCDHR. Wolfgang Hladik, MD, MSC is a public health researcher working in Uganda for the USA CDC. Dr. Hladik has been working with the Uganda National Association of the Deaf, and their goal is to learn about the health of deaf people in Uganda. They hope to develop a health survey in Ugandan Sign Language (USL). Dr. Hladik spent the day in Rochester meeting with NCDHR and NTID faculty and staff to learn about NCDHR research methods. After a day full of meetings and discussions regarding what NCDHR does here in Rochester, NY, Wolfgang Hladik left with a better understanding of the operations and how NCDHR creates culturally and linguistically accepted surveys for the Deaf Community in the US. NCDHR enjoyed hosting Wolfgang for the day and looks forward to possibly working with him and Uganda in the years to come.

What is Diversity?

Q & A regarding Research and Diversity at NCDHR

Q: What is diversity?

A: Diversity refers to any characteristic that makes people different from one another. For example - age, gender, race, ethnicity, religion, or sexual orientation.

Q: Why is diversity important in research?

A: We can learn a lot from research programs that include all kinds of people—older, younger, women, men, and people from different cultures, different backgrounds, and different lifestyles.

Research studies that have diverse participants can help us learn how programs or treatments might work with different kinds of people. Also, research studies that have diverse participants are usually more representative of the general population. This means that we can be more confident that what we learn from a research program can be applied to other groups of people.

For example, if a research study for a new medication only included white, middle-aged men, researchers wouldn't be able to learn how that medication affects women, people in different age groups, or people of different races.

Q: Is diversity important in research with Deaf people and people with hearing loss?

A: Yes! There is very little research about Deaf populations and people with hearing loss. Having diversity in deaf and hard-of-hearing research helps researchers have a more complete picture of the health of deaf and hard-of-hearing people. What we learn from a diverse group here in Rochester can help improve the health of other deaf and hard-of-hearing communities around the US.

Q: How can we make sure NCDHR research programs have diverse participants?

A: Spread the word about our research programs! We will attend many Rochester events over the next several months, to meet new faces and to network with friends like you.

Did you know?? There are 3 research opportunities at NCDHR!

DEAF HEALTHCARE SURVEY

- Are you 18 or older and Deaf?
- Want to give feedback about your healthcare experiences?

Take the DEAF HEALTHCARE SURVEY!

- ✓ ASL / sign language survey about the healthcare experiences of Deaf people
- ✓ Available on a touch-screen computer, takes 45-60 minutes
- ✓ Different from the 2008 NCDHR Deaf Health Survey

If you are aged 40-70, Deaf, and live in the greater Rochester area, there are 2 other research projects you may also qualify for:

HEALTH LITERACY & CARDIOVASCULAR RISK

- What cardiovascular risk factors do you have?
- We want to learn more about the impact that health knowledge and literacy has on your risk factors!

What you will do:

- ✓ Several short surveys and interviews in one appointment (60-90 min)

DEAF WEIGHT WISE

- Would you like to exercise more?
- Learn about healthy cooking and eating?
- Lose weight and become more fit?

Join Deaf Weight Wise (DWW) now!

What you will do:

- ✓ Participate in a 16-week group program, conducted in ASL
- ✓ Learn about healthy living, healthy food / cooking, and fun ways to be active
- ✓ Visit the NCDHR offices 5 times over 2 years to take ASL health surveys and have physical measurements taken (height, weight, blood pressure, blood samples)

For more information about ANY of these programs:
 Email: NCDHR@urmc.rochester.edu
 Videophone: 585-256-2776
www.urmc.edu/ncdhr

NCDHR
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But we can't do it alone...we need your help. We know that we have not reached some members of the Rochester Deaf community. We are trying new ideas to help reach out to people we don't already know—including churches and organizations around Rochester that may not know about NCDHR.

And thanks to all of you who have already told your friends about your research experience! About 25% of our Deaf Weight Wise participants learned about Deaf Weight Wise from their friends who are already in the program!

For more information:
 Click on the image for more information on the research studies.

Visit our website: www.urmc.edu/ncdhr



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Working for a Healthy Deaf Community



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