# Healthy Signs Research **NCDHR Launches a New Survey: Deaf Health Survey 2013 Other Community Engagements Discovering Deaf Worlds: NCDHR** Receives a Visit from the Philippines **Rochester Deaf Festival 2013:** An Update NCDHR **HAPPENINGS External Advisory Committee:** Friends reunite and welcome the new **Summer Interns: NCDHR welcomes** 4 student interns Dr. Thomas Pearson (TAP): An **Important Announcement** Acceptance to APHA: Presentations and Films accepted Don't Miss NCDHR's this year Community Forums! Planning the next 5 years **Completion of the Preventive** Cardiology Fellowship: Dr. Lisa Lowenstein and Dr. Denise Thew



# **Don't Miss NCDHR's Community Forums!**

# **COMMUNITY FORUMS**

What should NCDHR pursue for the NEXT 5 YEARS?

#### We need your help!

Join us for the unique opportunity to help strategize health priorities and direct research programs that are important to you!

- Tell us your community health concerns
- Share your knowledge

- · Guide our research direction
- Learn about our surveys and research results

Hosted by



**Deaf Health Community Committee** 

WEDNESDAY JULY 24TH, 2013 6:30PM-8:30PM

STAYBRIDGE HOTEL & SUITES 1000 Genesee St– Rochester, NY 14611

TUESDAY, AUGUST 13TH, 2013 6:30PM-8:30PM

STAYBRIDGE HOTEL & SUITES 1000 Genesee St– Rochester, NY 14611 Hosted by



**Healthy Living with Hearing Loss Committee** 

TUESDAY AUGUST 6TH, 2013 6:30PM-8:30PM

ST. PAUL'S EPISCOPAL CHURCH 25 Westminster Rd– Rochester, NY 14607

WEDNESDAY AUGUST 14TH, 2013 6:30PM-8:30PM

ST. PAUL'S EPISCOPAL CHURCH 25 Westminster Rd– Rochester, NY 14607



ASL interpreters, Real-time captioning and Assistive listening loop will be available for all meetings. If you require additional ADA accommodations please contact: Kelly Matthews, kelly matthews@urmc.rochester.edu OR (585) 512-8519 VP

#### FREE COFFEE AND DESSERTS PROVIDED



FREE Parking and Bus Passes available

Bus Lines near all locations

Rochester Prevention Research Center



Other Community Engagements

NCDHR HAPPENINGS

# NCDHR Launches a New Survey

Deaf Health Survey 2013



# Don't be left out... Take the Deaf Health Survey 2013 Now! Help Our Community Learn More about Deaf Health

#### What is the Deaf Health Survey (DHS) 2013?

DHS 2013 is a sign language health survey developed by NCDHR. The survey asks about health topics like these:

- · going to the doctor
- heart health
- feelings
- smoking
- and other things in life that can affect health

#### Why is the DHS important?

Every year, the U.S. Centers for Disease Control and Prevention (CDC) picks random households to take a health survey over the telephone. Deaf people are not able to participate in national telephone surveys. So, there is not a lot of health information available about Deaf populations.

NCDHR created the first Deaf Health Survey in 2008, so that Deaf people could participate in the same kind of health survey that some hearing people take. In 2008, over 500 Deaf people took the survey!

#### Why should I take the survey?

Surveys help communities to learn more about their own health. Survey answers can be grouped together to show information, such as:

- How many Deaf people in Rochester have ever had a heart attack?
- How many Deaf people in Rochester are regular smokers?
- How many Deaf people in Rochester have had a check-up with their doctor this year?

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#### For more information:

Check the NCDHR website: www.urmc.edu/ncdhr
Watch this video

This information can help community members, healthcare providers, researchers, and policy makers to understand more about a community's health and needs. It can also help organizations and programs to better understand their community.

#### Is the survey confidential / private?

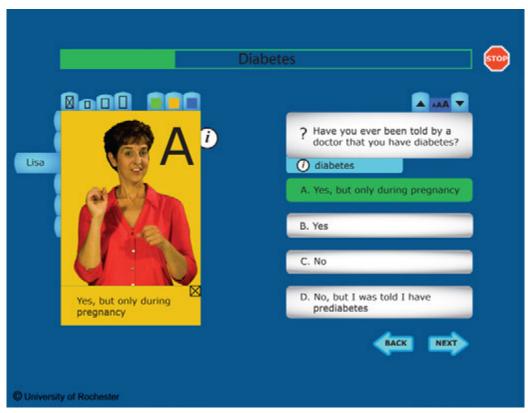
Yes! The survey does not ask for your name. No one will know your answers. All answers are combined into a private database.

#### Make an appointment now!

Any Deaf person age 18 or older can take the survey. NCDHR will host events and will go to Deaf organizations/meetings around Rochester to offer the survey.

To make an appointment, or to invite NCDHR to your organization, please contact:

Kelly Matthews, NCDHR research coordinator Kelly Matthews@urmc.rochester.edu
VP: 585-512-8519



Caption: A lot of NCDHR surveys look the same, because they use the same survey software program. How will you know you are taking the DHS 2013? You will see the DHS 2013 logo attached to the computer.





# Other Community Engagements

NCDHR HAPPENINGS

# **Discovering Deaf Worlds**

# NCDHR Receives a Visit from the Philippines

On May 15, Discovering Deaf Worlds brought a delegation of 11 signing Deaf leaders from the Philippines to America to visit several institutions and organizations to advance their self-determination as well as capacity building. Some of the institutions they visited were NCDHR and the Deaf Wellness Center here at the University of Rochester Medical Center (URMC). Dr. Michael McKee gave a presentation regarding communication accessibility in Doctors' offices. Matthew Starr explained the concepts of Community-Based Participatory Research. Dr. Denise Thew presented about mental health in the Deaf community.

To learn more about Discovering Deaf Worlds, click here.



# **Rochester Deaf Festival 2013**

### An Update

On June 8, 2013, NCDHR attended the Rochester Deaf Festival. While the weather was miserable, with rain showers throughout the day, the attendance at the event remained substantial. Jamie Marsden and Kelly Matthews ran the NCDHR table. Roughly 50 people stopped by the NCDHR table to learn more about NCDHR and discuss research and health in the Deaf Community. The main focus for NCDHR for the day was the announcement of their new study, the Deaf Health Survey 2013, and the promotion of the Deaf Farm Stand, to be jointly run by NCDHR and the Rochester Recreation Club for the Deaf (RRCD), in collaboration with FoodLink. The Farm Stand is held at RRCD every Saturday from July 6-September 7.

Jackie Pransky and Dr. Mike McKee ran a table for Mike's study, "Health Literacy and Cardiovascular Risk Factors". To learn more about his study, <u>click here</u>. Val Nelson-Metlay, with the assistance of a few of the DHCC members, ran a table for DHCC. The atmosphere was light, despite the torrential downpour at times, and people enjoyed the events for the day and the opportunity to catch up with old friends. NCDHR is grateful to everyone that attended the day's





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# **External Advisory Committee**Friends reunite and welcome the new

On June 18 and 19, several people from around the US flew to Rochester, NY for the annual External Advisory Committee meeting. June 18th was an evening of welcoming and catching up, and Deaf community members, members of the community of people with hearing loss, and the NCDHR staff were invited to socialize and welcome the EAC members. While the evening was filled with catching up, some new faces were also introduced to the communities and NCDHR staff. Debra Patkin, an attorney with the NAD, attended the EAC as a new member this year. Sam Trychin came as a substitute for Brenda Battat from the national HLAA. NCDHR was happy to welcome back Alan

Hurwitz, current chair of the EAC and president of Gallaudet University, Senda Benaissa, a research associate for the Gallaudet Research Institute, Pamala Lloyd, Chief of the Community Services of North Carolina, Division of Vocational Rehabilitation, David Ebert, medical director of the Deaf Access Program, Philip Zazove, Chair of the University of Michigan Medical School's Department of Family Medicine, and Ken Levinson, partner at Kornetsky & Associates, a CPA firm in San Francisco.

After the welcoming at the Saunders Research Building, the EAC, Drs. Thomas Pearson, and Steven Barnett traveled to the Strathallan hotel for a dinner meeting. On June 19th, the business part of the EAC began with an all-day meeting. The EAC members discussed NCDHR's accomplishments through the previous years, as well as the opportunities for growth, where NCDHR could improve. By the end of the day, the EAC provided suggestions to the NCDHR, advising ways the NCDHR could further improve in the year to come.

NCDHR cherished their time with the EAC and greatly appreciated their feedback. As the year moves on, NCDHR will work to incorporate the EAC's recommendations into their ongoing work.





#### **Summer Interns**

#### NCDHR welcomes 4 student interns

NCDHR recently welcomed 3 student interns and one student from the **SURF** program to assist us with multiple summer projects. They are active in a variety of projects that will utilize their talents while receiving a valuable education and work experience. Will and Paul are assisting Tiffany Panko and Dr. Michael McKee with the "Use of Emergency Department by Deaf ASL Users" project, in addition to the Deaf Seniors Perceptions Project directed by Drs. Tamala David and Michael McKee. Madeline and Jennifer are working with Dr. McKee on the "Aging with Hearing Loss" project. Their responsibilities on these projects include recruitment, facilitating and

RESEARCH

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assisting multiple focus groups, data collection, data coding and analysis. These projects will help us learn more about Deaf Health in a variety of health care areas. The information learned by these projects will hopefully lead to useful interventions to help the Deaf Community. The student interns are also participating in Dr. Scott Smith's class on community-engaged health research methods. At the completion of their summer internship, the students will provide an educational workshop for Deaf attendees at the Deaf Health Talks at the end of July.



**Madeline Beach** Madeline is originally from the Chicago area. This fall she will be a senior at Boston University, majoring in Mathematics with a track in Statistics. She is also minoring in Deaf Studies. She hopes to one day go to graduate school for a PhD either in statistics biostatistics or SO she can apply knowledge that research in the fields of deafness and gerontology.



William Fetzer
William is from Indiana.
He is currently enrolled
at Indiana University –
Purdue University of
Indianapolis (IUPUI),
where he is double
majoring in Psychology
B.S. and Neuroscience
B.S. His research
interests are:
psychopharmacology,

neuromechanism of addictions, and community-based qualitative research. His career goal is to be a neuropsychiatrist or neurologist at a teaching hospital, or to set up his own practice.



Jennifer Hu

Jennifer is a rising senior at Swarthmore College, majoring English literature double-minoring in biology and Chinese. After graduation, she will be attending the University of Rochester Medical School. Growing up with a deaf younger sister, she has always been interested in learning more about, and working with, the Deaf community, though she knows she still has a long way to go in learning American Sign Language and understanding Deaf Culture. This summer, she is participating in the University of Rochester SURF Program for pre-medical students.



**Paul Silvasi** 

Paul Silvasi is originally from Mt. Pleasant, Wisconsin. is a graduating Psychology major at the Rochester Institute of Technology and in this upcoming Fall semester, he will be a student at Gallaudet University for their Clinical Psychology PhD program. He aspires to work as a Clinician or a Therapist, after receiving his doctorate, and with experience, hopes to become a professor of Psychology at either Gallaudet University or at Rochester Institute or Technology. Another goal he has in mind is in the field of Forensic Psychology as a Criminal Investigator for the CIA or FBI.

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# Dr. Thomas A. Pearson (TAP) An Important Announcement

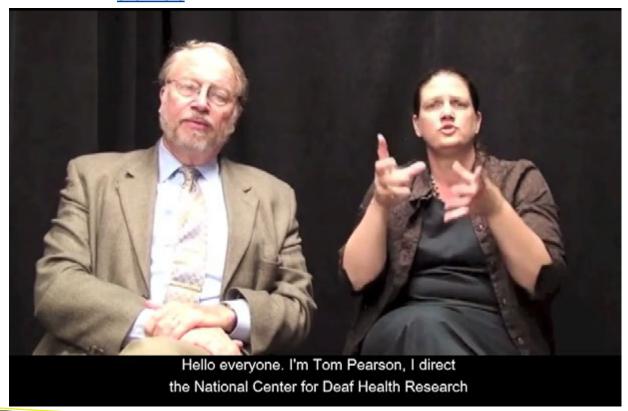
Dr. Thomas A. Pearson (TAP), the founding director of NCDHR, will be leaving the University of Rochester for a new job at the University of Florida. During his 16 years at UR, TAP has established and led many successful programs at UR, including NCDHR and the internship and fellowship programs that work with NCDHR. We are confident that these strong programs will continue after his departure.

Over the next two months, in preparation for TAP's departure, there are many transitions that will happen at UR. UR is committed to the ongoing success of NCDHR. Soon, UR and NCDHR will share information about NCDHR transitions.

While NCDHR is very excited for this promotion in his life, they will also greatly miss Dr. Pearson. NCDHR looks forward to the ongoing communication with Dr. Pearson and wishes him the best in his future endeavors!

For the full article from the University of Rochester, <u>click here</u>.

To see Dr. Pearson's announcement on youtube, interpreted with closed captioning, **click here**.





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## NCDHR HAPPENINGS

# Acceptance to APHA

# Presentations and Films accepted this year

NCDHR has recently had 4 different presentations accepted to the American Public Health Association (APHA) conference held in Boston, MA this year. NCDHR will be presenting 3 short films and 1 poster. Presentations will begin on Monday November 4, 2013 and run through Wednesday November 6, 2013. Click on the links below to read more about the conference and the presentations.

First Author	Title	Abstract
Erika Sutter, MPH, Amanda O'Hearn, PhD, Lori DeWindt, MA, Carlene Mowl, MPH, Kimberly Kelstone, CI, CT, Steven Barnett, MD, and Thomas A Pearson, MD, MPH, PhD	Adapting informed consent processes with deaf American Sign Language (ASL) users: Experiences from the Deaf Weight Wise study	Researchers and community members adapted a written English consent document into a dialogic, "novella"-style ASL video, a format used with health education materials because it is language accessible and culturally congruent. Click to read more.
Steven Barnett, MD, Nancy Chin, PhD, MPH, Kimberly Kelstone, Cl, CT, and Jeret Hackbarth.	Community Participatory Research with Deaf Sign Language Users for Identifying Health Inequities	This film is an adaptation, presented in American Sign Language (ASL) with English captions, of a peer-reviewed written English public health journal article. Click to read more.
Jamie Marsden, MSSeD, Erika Sutter, MPH, Val Nelson-Metlay, BFA, Kelly Matthews, MSW, and Lori DeWindt, MA.	Deaf Health Survey 2013	This film was developed as a tool to help recruit deaf American Sign Language (ASL) users to surveillance and research studies at the NCDHR. Click to read more
Amanda O'Hearn, PhD, Erika Sutter, MPH, and Lori DeWindt, MA.	An American Sign Language Consent Film	A filmed, scripted scenario was created in which Deaf actors portray researchers and participants discussing the informed consent process. Click to read more.



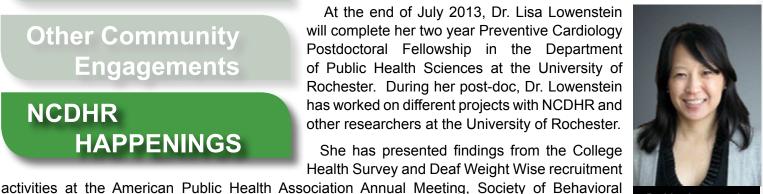
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### **NCDHR HAPPENINGS**

# Completion of the **Preventive Cardiology Fellowship** Dr. Lisa Lowenstein

At the end of July 2013, Dr. Lisa Lowenstein will complete her two year Preventive Cardiology Postdoctoral Fellowship in the Department of Public Health Sciences at the University of Rochester. During her post-doc, Dr. Lowenstein

She has presented findings from the College Health Survey and Deaf Weight Wise recruitment



Dr. Lisa Lowenstein

Medicine Annual Meeting, and American Heart Association Epidemiology/Nutrition, Physical Activity, and Metabolism Annual Meeting. She has worked with other NCDHR researchers to write two research articles and hopes to have them submitted to peer-reviewed journals.

In addition to her work with NCDHR, Dr. Lowenstein published 2 papers from her dissertation in Childhood Obesity. She has multiple papers in the pipeline that were/will be submitted to peer-reviewed journals covering provider-patient communication; quality improvement in the neonatal intensive care unit to improve the utilization of human milk, effect of omega-3 fatty acid supplementation on fatty acid composition, and the evaluation of a healthy lifestyle intervention.

She will continue conducting research to improve healthcare delivery and has accepted a position with Dr. Supriya Mohile in the Wilmot Cancer Center at the University of Rochester. In this new role, she will assist the implementation of a multi-site clinical care intervention to improve the care of geriatric cancer patients; oversee data collection and analysis; and continue to communicate research findings at scientific conferences and peer-reviewed journals.

#### Dr. Denise Thew



Dr. Denise Thew completed her 3-year long Postdoctoral fellowship in Preventive Cardiology in the Department of Public Health Science at the University of Rochester Medical Center. During her fellowship, Dr. Thew completed the Masters of Science in Clinical Investigation degree. This degree helped to increase her knowledge and understanding about epidemiology, the healthcare system in the U.S., research skills, and grant writing skills. Additionally, she engaged in several research activities she needed to advance her career as a researcher at URMC. She was involved in several stages of the Deaf Weight Wise project including the role as a DWW counselor. She was also involved with the CDC-funded project on Intimate Partner Violence (IPV) with the Deaf Wellness Center. This project is lead by Dr. Bob Pollard. During her fellowship, she published the Deaf Strong Hospital article with several other co-authors (Dr. Smith, Dr. Chang, and Matt

Starr), Engaging the deaf sign language community: Lessons from a community-based participatory research center (with Dr. McKee et al), Ethical Issues in Conducting Research with Deaf populations (in press with Drs. McKee and Schlehofer) and has couple of articles in press on the Intimate Partner Violence research. She has given several national presentations on her projects and on public and mental health faced in the deaf population. As a psychologist with public health/clinical research training, Dr. Thew will continue to be involved on various research projects with Dr. Bob Pollard at the Deaf Wellness Center, including the IPV and the Informed Consent projects.



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







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