

Healthy Signs



National Center for Deaf Health Research

Winter 2008

Mission of NCDHR:

To promote health and prevent disease in the Deaf population through community-participatory research.

Save the Dates!

April 29 - May 1, 2008
CDC Site Visit

May 19 - 20, 2008
Third Annual Meeting
of the NCDHR's
External Advisory
Committee (EAC)

Contact Us:

NCDHR
P.O. Box 278990
Rochester, NY 14627

120 Corporate Woods
Suite 350
Rochester, NY 14623

(585) 758-7804 TTY
(585) 276-2122 VP
(585) 424-1469 FAX
www.urmc.edu/ncdhr
ncdhr@urmc.rochester.edu

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Deaf Health Survey Update

Deirdre Schlehofer, M.Phil.

Good news! The Deaf Health Survey will be launched mid-February. Since the summer of 2007, the research team conducted and completed 32 in-depth cognitive interviews by the end of December. The purpose of the interviews was to learn from diverse Deaf participants about their perspectives and reactions to the health survey on the computer screen (also known as interface).



Deaf Health Survey interface. Patrick Graybill is one of the six sign models that will appear on the interface.

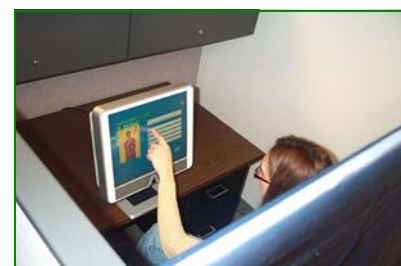
Questions were asked of the survey-takers such as: Why did you pick a particular ASL model? Did you understand the questions? What medical terms are not familiar to you? How can we help you understand the survey better?

The collected responses are an important part of an on-going review in order to improve the survey. Many committee members and community-based contractors have worked tirelessly to make the complexities of the interface more workable. The University of Rochester's RSRB (Research Subjects Review Board), charged with protecting the rights and welfare of the study volunteers, is reviewing all materials. Once approved, the health survey will be released soon.

The survey will display videos in ASL, English-like sign language and captioning. Most of all, **thank you** for your input and support of NCDHR.



Filming of the Deaf Health Survey at RIT.



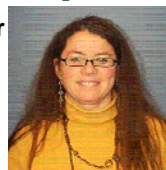
Survey will be conducted in strict confidentiality at NCDHR and at some Deaf organizations.

Messages from NCDHR Leadership:



Steven Barnett, MD, Associate Director

Welcome to this edition of Healthy Signs, the NCDHR newsletter. This issue highlights recent accomplishments of NCDHR and our partners. The newsletter also describes the progress of our research team: DHCC members, researchers and staff are working together to create the Deaf Health Survey. Soon we will learn from Deaf people about the important health issues in the Deaf community. Look for more information about the Deaf Health Survey on our website, or contact NCDHR by VP or e-mail. Also, you can add your name to the NCDHR contact list, and one of our staff can contact you about NCDHR research. The Deaf Health Survey is almost here!



Julia Aggas, MS, DHCC Chair

"Spread the word!" The Deaf Health Survey will prove to be highly beneficial to the Deaf communities. For decades, public health has overlooked Deaf people who communicate primarily in ASL. The health surveys are done by telephone, which is inaccessible for most Deaf persons. The survey, which will be totally confidential, will be shown in ASL, English-like sign language and captioning will be accessible for all. Once we obtain the data, we can then find out what health disparities exist in the Deaf community and develop culturally and linguistically appropriate intervention programs to reduce or eliminate health disparities. "Spread the word!" to your Deaf relatives, friends and co-workers!

NCDHR Open House



Open House visitors packed NCDHR offices and hallways.



Visitors trying out demos of the Deaf Health Survey and giving feedback to **Betsy Finigan, MD** (in blue), one of the NCDHR's researchers.



Julia Aggas, MS (in green), Chair of DHCC, encouraging children doing physical activity with jump-ropes.



Visitors lining up to enjoy Italian-style buffet at NCDHR.

NCDHR Happenings

Pat Sullivan, MSW, LCSW-R, a member of DHCC, was recognized by a national educational organization with "National Heart of Social Work Award," October, 2007 in San Francisco, for his lifetime achievement in field instruction.

Camille Martina, PhD has joined NCDHR as its newest program evaluator. Since 1999, Dr. Martina has evaluated programs in secondary, higher education and adult education sciences and health programs for the National Science Foundation, National Institute of Environmental Health Sciences, Howard Hughes Medical Institute and was an educational consultant for the Agency for Toxic Substances and

Disease Registry. She will be working closely with DHCC to develop a committee evaluation plan.

Deaf Wellness Center (DWC) was honored by the American Psychiatric Association with 2007 Psychiatric Services Bronze Achievement Award. Three members of the NCDHR Research Subcommittee who also work at DWC are **Amanda O'Hearn, PhD, Robert Pollard, PhD** and **Anne Steider, PhD**.

The Deaf Health Community Committee welcomes new members: **Mike McKee, Tiffany Panko, Alexander Pouliot, John T. Reid** and **Audrey Schell**.

DHCC also bids farewell to two former members who have served the two 3-year term: **Brian Piotrowski** and **Vicki Hurwitz**.

Carolyn Stern, MD, of the Education & Training Subcommittee, presented, "Navigating Your Way Through The Healthcare System" at the Iowa Association of the Deaf Conference, and on "Diabetes" at the Alabama Association of the Deaf Conference, Summer, 2007.

Betsy Finigan, MD, member of the NCDHR Research Subcommittee, presented to Deaf Women of Rochester on preventing heart attacks and strokes (January 27).

NCDHR's First Open House

NCDHR had a successful and fun-filled open house on November 16, 2007 at Corporate Woods. Visitors, both adults and children from the Deaf community packed the offices and hallways (see photos left). Besides our awesome Italian-style buffet feast, visitors were drawn to the first ever demo of the Deaf Health Survey. Tours of NCDHR's Deaf-friendly offices and meeting rooms were proudly guided by NCDHR's full time staff,

Susan Demers Postlethwait, MS, **Susan Demers Postlethwait, MS**, NCDHR Coordinator, **Deirdre Schlehofer, M.Phil.**, Research Coordinator and **Matthew Starr, MPH**, Senior Instructor, members of the Deaf Health Community Committee and NCDHR researchers. Visitors also had opportunities to socialize as they saw their friends and met new people. Children were busy jumping ropes given out by NCDHR to promote their wellness.

Steven Barnett, MD, Interim Associate Director and **Julia Aggas, MS**, Chair of DHCC, gave opening remarks to visitors, welcoming them to the nation's first community-based participatory research center that focuses primarily on ASL communities.

For those who missed our first open house, we hope to schedule another one in the near future!

Deaf Elderly Life History Initiative

If the Deaf Elderly History Initiative grant is awarded, Rochester Recreation Club for the Deaf (RRCD) will become a key partner with NCDHR. **Steven DeBottis, Colleen Pouliot, MS**, and **Sally Taylor, MA**, of RRCD will be co-investigators along with **Nancy Chin, MPH, PhD**, principal investigator, to better understand how Deaf elders have successfully

negotiated and managed normal life crises such as adolescence, illnesses, injury, and transitions from school to work. Findings will be collected through interviews conducted in ASL.

Also part of this research team are members of DHCC: **Jessica Cuculick, MSW, Patrick Graybill, MS, Ken Kelbaugh, MS, Patrick Sullivan, MSW**,

and **Tracy Washington, BS**. NCDHR organizational support will be provided by **Susan Demers Postlethwait, MS** and **Matthew Starr, MPH**. **Steven Barnett, MD** and **Deirdre Schlehofer, M.Phil.** will serve as medical and linguistic consultants, respectively.

Let's hope that we do get the grant!