

Healthy Signs



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

MEDICINE of THE HIGHEST ORDER

National Center for Deaf Health Research January 2009

Mission of NCDHR:

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

Grant Application Update:

The renewal grant application that we submitted in October will go through final review in mid-February, according to the Centers for Disease Control and Prevention (CDC). Shortly after that, the CDC will let us know if we will be funded for the period Oct. 2009 through Sept. 2014. Watch the NCDHR-News e-mail listserv for updates! See below for how to subscribe to the listserv.

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New Staff at NCDHR

Thomas Fogg



The NCDHR welcomes **Kimberly Kelstone, CI/CT**, as our new Staff

Interpreter! Kim will be on the job full time at the NCDHR offices, interpreting for meetings and casual encounters as well as coordinating outside interpreter services for the Center.

Kim has been interpreting for over 18 years. She previously worked at MCAHI (Deaf and Hard of Hearing Program) as community-

based interpreter, with another interpreter, Chris Kelley, who is now a member of Deaf Health Community Committee. Rochester has been her home off and on ever since she graduated from high school, originally coming here to attend RIT for an engineering degree. Her interpreting experience covers almost every possible situation, from education to medical to performing arts.

She is currently the president of Rochester's local interpreting organization, the Genesee Valley Region Registry of Interpreters for the

Deaf (GVRRID). She has presented at the local and the national level, including the most recent RID national convention in San Francisco, and the Texas Society of Interpreters for the Deaf / Region IV convention in Houston, TX.

She is enjoying her new position with NCDHR and looking forward to the adventures this new opportunity will bring.

She can be reached at kim_kelstone@urmc.rochester.edu or 866-901-0727 VP (585-758-7792 Voice).

Welcome Kim!

DWC/NCDHR/ASADV Collaboration Leads to New CDC Grant Request

Robert Pollard



Close teamwork between the University of Rochester's Deaf Wellness Center (DWC), NCDHR, and Advocacy Services for Abused Deaf Victims (ASADV) has led to a new grant application

proposing "*A Pioneering Study of Partner Violence Perpetration Affecting the Deaf Community*." The grant proposal was sent to the Centers for Disease Control and Prevention (CDC) last week.

The 3-year project involves four "focus group" meetings around the U.S. with professionals who work with deaf victims and perpetrators ("batterers," "offenders") and then a series of 67 videophone interviews with deaf victims and deaf perpetrators. The goal of the study is to better understand the characteristics of partner violence ("domestic violence") perpetrators who abuse deaf people and also to understand how partner violence involving deaf people is similar to, or different from, how partner violence happens among hearing people. For example, we

suspect that partner violence with deaf people often includes controlling the deaf victim's access to communication.

The idea for this project grew over several years. When NCDHR designed the Deaf Health Survey last year, we included several questions about partner violence. We expected these questions to be helpful to the DWC and ASADV, who already had been doing a number of projects together. When the survey data were analyzed, high rates of partner violence were found.

During the series of Deaf community meetings last fall, when NCDHR was seeking input about research priorities, it was clear from a review of these data that community members wanted partner violence to be one of the research priorities at NCDHR. So NCDHR collaborated with the DWC in writing this new grant proposal. The proposal included a summary of the data collected during the Deaf Health Survey which should strengthen the grant application. The CDC will review the grant and make a funding decision by June.

NCDHR health survey during NTID's 40th Anniversary Reunion Deirdre Schlehofer



During June 26-28, 2008, more than 700 alumni attended the NTID 40th Anniversary Reunion.

The NCDHR exhibition booth was a great opportunity for people to ask questions about health research with Deaf people, and 215 people took the Deaf Health Survey (DHS) in private booths during the event. This remarkable success was due to NCDHR staff and Deaf Health Community Committee members working together along with support from NTID, Deaf community members and alumni.

Before and after the reunion, another 302 from Rochester took the survey. What did NCDHR do with the data? We organized 5 town hall meetings at NCDHR during August and September 2008. Members of the Rochester Deaf community attended

and we shared preliminary survey findings from the first 283 people who took the DHS. All of the data are completely anonymous – the survey data contains no names. Community members gave valuable input on the analyses and health priorities.

We continue to fully analyze the DHS data. We plan more town hall meetings in spring and summer 2009 to get community input to interpret findings. Working with DHS data, Deaf communities can identify health priorities for future interventions and research.

We have a challenge. Getting input from the Rochester Deaf community during town hall meetings is straight forward, but we also need the input from the NTID alumni community who live outside Rochester. We are looking for ways to share and discuss data analyses

with NTID alumni who are unable to show-up in-person at town hall meetings in Rochester. Please send us your ideas on how to involve the national NTID alumni community in discussing survey data and helping to identify Deaf community health priorities.

The NCDHR has an e-mail listserv for people that care about the NCDHR. It's called the NCDHR-News.

What is a listserv? A long list of e-mail addresses. When we send a message to the listserv, it goes to everyone on the list.

What sort of messages will we send? We'll send this newsletter, and occasionally other announcements.

How often will we send messages? Two or three times each month. Every message will be interesting and important.

How can I sign up? Just ask! Send us a note at ncdhr@urmc.rochester.edu.

We will no longer be invisible! Jess Cuculick and Matthew Starr



Today, everywhere in the country, numerous community health coalitions, often represented by members of ethnic groups, work collaboratively with public

health officials to eliminate health disparities among minorities. One example here in Rochester is the Community Advisory Board (CAB) of the newly formed URM Center for Community Health (www.urmc.edu/communityhealth).

Dr. Tom Pearson, NCDHR Program Director and a member of the CAB, has long recognized that the Deaf community tends not to be considered a cultural group in spite of the fact that the Deaf community shares a common language (American Sign Language), has a shared history, and shared behavioral norms. As a result, Deaf communities typically are not represented in these coalitions. By advocating for the Deaf community, Dr. Pearson convinced the CAB to invite us to give a presentation to their members, "Partnering with members of the ASL community: a linguistic minority group." Our objective was to increase awareness that the members of the Deaf community are descendants of a rich culture and history, and that the Deaf community is indeed an ethnic group.

We described how health promotion interventions have been inaccessible to the Deaf community. Health

survey data, which are a prerequisite for funding health programs, are typically collected through telephone interviews, and thus exclude health information from the Deaf community. Deaf communities may experience health disparities, possibly due to communication inaccessibility and insensitivity in healthcare settings. This problem statement was a powerful argument leading to the funding of NCDHR. We proudly reiterated that NCDHR is the first of its kind in the country and is guided by principles of community-based participatory research with the Deaf community.

We further enlightened our audience by explaining how the leaders of Deaf communities are fighting to eliminate prevailing perspectives that deafness is a condition that needs medical intervention, especially when those attitudes are directed toward culturally Deaf people.

At the end, we knew we had captivated the audience when several hands rose to ask us questions. The chair of CAB, Dr. Andrew Doniger, Director of the Monroe County Department of Public Health, thanked us and affirmed that the Deaf community shall be represented in future CAB meetings.

We thank Dr. Pearson for his advocacy, leading to hopes that the Deaf community will no longer be invisible and that its members will become active participants in this community's efforts to improve the health and healthcare for all Rochesterians.