

Season's Greetings

Healthy Signs



MEDICINE of the HIGHEST ORDER

National Center for Deaf Health Research December 2009

Mission of NCDHR:

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

SAVE THE DATE

Deaf Health Talk about Diabetes

TBA January, 2010

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2000—2010: Ten Years Retrospective of Deaf Health Research



"It's amazing how Deaf Health Research has grown in the last ten years!"

reflected Dr. Tom Pearson, NCDHR Program Director. "At the start of 21st century, funding for deaf health research was paltry, and so there was very little data about the health status of Deaf people. Research training grants for promising Deaf and hard-of-hearing researchers were almost nonexistent. In the last ten years, there have been significant strides in Deaf Health Research, and I cannot possibly list every accomplishment and undertaking. Granted, we do have a long way to go, however it is my great pleasure to outline so many positive outcomes just to show how far we have come."

Funding: More than \$10 million has come to Rochester to bring deaf health research out of obscurity, elevating its prominence to unprecedented levels within the applied public health research enterprise. The likelihood of acquiring more grants and contracts increases as NCDHR publicizes new research data and presents its findings.

Community-Based Participatory Research (CBPR):

The collaboration between the University of Rochester Medical Center, an academic health center, and

its partners, especially the Deaf Health Community Committee (DHCC), has been the cornerstone of our center's growth. Together, both researchers and community partners have navigated many learning curves over the years, leading to a maturing partnership. This incredible journey of building an enduring academic-community relationship began in early 2000 when Dr. Steven Barnett



successfully received a grant from the Association of Teachers of Preventive Medicine and the CDC to establish a community-based Deaf Health Task Force (DHTF). With assistance from the Finger Lakes Health Systems Agency, 27 representatives of the

Rochester Deaf community, academic health centers, healthcare and insurance organizations worked together to draft a report about barriers to healthcare faced by the Deaf population. In 2005, the Task Force became the DHCC as it convened its first



meeting, with Susan Demers at the helm.



Today, DHCC, with John T. Reid as its current chair, and NCDHR continue to work effectively hand-in-hand with the

goal of improving the health of the Deaf community.

Research: At the beginning of this decade, interested Deaf Health researchers could only be dismayed to learn how little data on Deaf Health data were available. Traditionally, public health surveillance relied heavily on telephone calls to collect data on health risk behaviors and health status, excluding Deaf people. Since its inception in 2004, NCDHR has accumulated a wealth of data collected from various surveys (both written and in ASL), focus group sessions, cognitive interviews, and more. Plans are now underway to conduct intervention research on obesity and possibly long-term studies of health in a group of Deaf people. In the future, these data will be available to any interested researcher for analysis, after usage guidelines are in place to ensure that anyone wishing to use the data will follow the principles of CBPR and conduct analyses in the context of cultural model.

Over 60 presentations and posters have been shared at local and national scientific conferences.

Training: In addition to Deaf Health Research, NCDHR and the University of Rochester provided numerous training opportunities for Deaf and hearing students in fellowships, internships, cooperative education and

more. To date, three Deaf individuals with doctoral degrees have joined the Preventive Cardiology Research Training Program, with a fourth coming on board in 2010. At least 15 medical, graduate, undergraduate and high school students have enhanced their research skills at NCDHR.

Through close collaboration with the UR's School of Medicine and Dentistry, a summer training program for disadvantaged students interested in health science careers became available to Deaf and hard-of-hearing high school students in 2009. Danica Metlay, now an RSD alumna, was the first Deaf STEP (Science & Technology Entry Program) student to be accepted.

Soon, NTID, Gallaudet University and NCDHR will embark on significant educational pipeline program to bring in and encourage qualified Deaf and hard of hearing students to pursue studies and careers in healthcare and research.

Advocacy: One of NCDHR's goals is to advocate for Deaf and hard-of-hearing people. In all of our grant applications, presentations, analyses and publications, we strive to educate everyone about recognizing Deaf ASL users as members of a cultural and linguistic minority. Furthermore, the landmark federal legislation, the Americans with Disabilities Act, often requires accommodations such as professional sign language Interpreters, in order to afford Deaf individuals the same opportunities as hearing persons. In this decade, NCDHR has seen mixed results in its numerous individual and systems advocacy. Below are some examples of our accomplishments and challenges:

Accomplishments: First off, the fact that NCDHR was twice awarded major grants from the CDC's Prevention Research Center Program confirms that our Deaf partners are acknowledged as a linguistic minority. This is, indeed a major accomplishment!

Other accomplishments include teaming up with the PRCs in North Carolina and Colorado to reach out to their Deaf communities as part of a research project in cardiovascular health behaviors.

Successful advocacy in securing interpreting services also enabled Deaf researchers and partners to present at one of the largest public health conferences in the world, the American Public Health Association's annual meeting, attended by about 15,000 people.

The Community Advisory Council (CAC) at the UR's Center for Community Health has welcomed Deaf representatives. The CAC engages in community-wide capacity building to reduce health disparities for all residents. In the past, such community-based councils would have overlooked Deaf people.

Challenges: Challenges remain. Here are a few examples of situations that we continue to work on:

- Our ability to publish research findings in peer-reviewed academic journals is a major factor in review of government research grant applications. Without a good track record of publications, it will be difficult for our Center to survive. Conversely, successful publication of our findings can lead to more grants. I am sure you have heard this phrase, "Publish or Perish!" Each academic journal recruits a pool of experts (often anonymous) to serve as reviewers of submitted manuscripts. But many reviewers have limited knowledge about Deaf culture, and many have misconceptions about Deaf culture. For example, a reviewer, with a background in Otolaryngology (an ear, nose and throat specialist), did not recommend a research proposal promoting health of Deaf people. His rationale was that there won't be any Deaf people in the future because of cochlear implants.

- Grant applications are reviewed in a similar way, so our grant applications continue to be at risk due to reviewers

without an understanding of Deaf culture.

To increase the likelihood of getting our articles published in peer-reviewed journals and securing new grants, we have to advocate for a diverse pool of reviewers that will embrace the cultural model of deafness.

The Next 10 Years: A new grant application, called, "The Rochester Deaf Community Cohort Program," has been submitted. If funded, it will establish the world's first population-based cohort study of Deaf persons. A "cohort" is a group of people that agree to take part in a health research study over a long period of time. The study will allow researchers to understand important health risks in deaf populations, and will lead to interventions that reduce health risks and increase knowledge about health in the Deaf community. The project will engage the community in planning and organizing the study, and in interpreting results. The study will transform communication and collaboration between an academic health center (the University of Rochester Medical Center) and the Rochester Deaf community. The research methods and data will support additional research studies, thereby ensuring equality, future capacity, and sustainability of Deaf Health research in the U.S.

