



*National Center for Deaf Health Research*

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**SEPTEMBER 28, 2005**

**FOR IMMEDIATE RELEASE**

## **Deaf Community Empowered to Decide Health Priorities**

Newest Community-Based Participatory Research Center Funded by Federal Government

A new program in Rochester, NY gives the Deaf community an unprecedented opportunity to express their concerns, issues and priorities when it comes to health care. Researchers will receive advice and guidance from throughout the community, in an effort to find solutions that are culturally and linguistically appropriate.

The Deaf Health Community Committee (DHCC), consisting of members of the American Sign Language (ASL) community along with clinicians and health insurance representatives, serves as an advisory group to researchers from the University of Rochester Medical Center who will conduct research to improve health and wellness in Deaf people and their families. DHCC has become the foundation of the newly established National Center for Deaf Health Research (NCDHR), housed at the University of Rochester Medical Center.

"We have truly been privileged to work with researchers in order to benefit our own community," acclaimed Patrick Graybill, Vice Chair of DHCC and retired professor of NTID. "It's an exciting project, long overdue!"

NCDHR has received a 5-year, \$3.7 million grant from the federal Centers for Disease Control and Prevention (CDC), based in Atlanta, GA. By making this grant, CDC has recognized that involving community people is the key to finding effective health promotion interventions that are culturally and linguistically appropriate for specific populations of different cultures, races and ethnicities. This is the premise of community-based participatory research. While CDC

supports 33 Prevention Research Centers (PRC) throughout the country, NCDHR is the only PRC that focuses on a population that communicates primarily in ASL.

“So little is known about disease trends, underlying attitudes, or health behaviors among Deaf or hard-of-hearing people,” says Thomas A. Pearson, M.D., Ph.D., MPH, and director of NCDHR.

DHCC chairperson Susan Demers Postlethwait explains that the mission of DHCC is to help Deaf communities, researchers, and health providers collaborate to promote understanding of the health needs of culturally Deaf people. “One thing that struck me was the term, ‘community-based participatory research,’” signs Postlethwait, a graduate of Gallaudet University and the Rochester Institute of Technology whose parents are Deaf and who hails from the Boston ASL community. “For decades, members of the ASL community have not had an unified opportunity to make their health concerns known. Pah! It's time for us to know our people better!”

Two members of the DHCC bring Deaf perspectives to the National Community Committee (NCC). The NCC comprises of representatives from all PRC’s community committees, including NCDHR, and they advise the CDC about national health issues.

Because of identified health disparities, the DHCC is proposing to hold a conference that will establish a national research agenda, which will focus on health promotion and disease prevention with Deaf people who communicate in ASL and their immediate families. Postlethwait believes that data pertaining to health issues and concerns should be collected from Deaf communities across the nation in addition to Rochester, NY. The resulting consensus document will help policy makers, funders, researchers, and community members to examine and address disparities among Deaf people.

DHCC’s long-term goal is to become a nationally recognized model that empowers the culturally Deaf community to achieve their health potential. Over time, NCDHR will work with other community committees for hard-of-hearing, late-deafened and other deaf and hard-of-hearing groups who are not members of the ASL community.

Contact Heather Pavey, NCDHR secretary, at (585) 276-2120 (TTY) or [Heather\\_Pavey@urmc.rochester.edu](mailto:Heather_Pavey@urmc.rochester.edu) if you wish to be included on our mailing list to receive future announcements about pilot study awards, fellowships, and research findings or to explore opportunities to collaborate with the NCDHR.

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