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FOR IMMEDIATE RELEASE

Rochester Starts First Deaf Health Research Center in Nation

CDC Grant Shines on Community Resources, Disease Prevention

The University of Rochester Medical Center, working with many community partners, received an unprecedented \$3.5 million grant to conduct the nation's first comprehensive health studies of individuals who are deaf or hard of hearing. The goal is to prevent disease and improve overall health in this population.

Funded by the Centers for Disease Control, the project begins this month. Initially researchers will convene deaf community focus groups; plan the best research methods to survey men, women and children; raise awareness among deaf people of opportunities to get involved in voluntary health studies; and build programs that will train doctors and break down existing communication barriers.

"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 chairman of the Medical Center's Department of Community and Preventive Medicine. "This project, in working closely with our partners, will allow us to discover and prioritize the health needs of the community. We also hope to serve as a national model for engaging people with disabilities in health research."

Although Pearson is the project leader, the research relies on a vast collaboration. Deaf and hearing experts are included from the UR, such as co-investigators Robert Pollard, Ph.D., director of the university's Deaf Wellness Center, and Steven Barnett, M.D., whose career as a Family Medicine physician has focused on deaf health research. Also included are experts from the National Technical Institute for the Deaf, a college of Rochester Institute of Technology; Rochester School for the Deaf; Finger Lakes Health Systems Agency; The Health Association; and the Monroe County Department of Health. An external advisory committee chaired by T. Alan Hurwitz, Ed.D., vice president of RIT and Dean for NTID, will have

representatives from Gallaudet Research Institute and the International Federation of Hard of Hearing People. In all, the team consists of 25 funded individuals, plus a small army of support staff.

In winning the grant, the UR and its partners join an elite group of 28 other medical centers funded by the CDC to establish research centers for disease prevention. Rochester, N.Y., seems to be the perfect place for such an historic initiative: As home to NTID and RSD, the area has one of the highest concentrations of deaf people in the United States.

Nationally, more than 4.8 million people cannot hear or understand speech, and approximately 28 million people have some degree of hearing loss. Yet medical literature shows that aside from hearing loss itself, little is known about the health status of the deaf and hard of hearing population. Even rudimentary data on health behaviors, risk factors and diseases is unavailable, health experts say.

Communication barriers may contribute to the problem. Many deaf people communicate through American Sign Language (ASL), which has different grammar and syntax than English. Others communicate through speech-reading, writing, speaking and other English-based methods. But few health care providers are proficient in ASL, or understand how to appropriately communicate with deaf patients.

Deaf and hard of hearing people also have less access to information from the ambient environment, information that hearing people often take for granted. So, for example, deaf youngsters do not benefit from overhearing the advice pediatricians give to their hearing parents; they do not get health information through radio or TV broadcasts, experts say.

“Finally, we have a research center that focuses on the overall health and wellness of people who are deaf or hard of hearing, and not just on their hearing loss,” says Matthew Starr, M.P.H., who is deaf and the director of The Health Association’s Deaf & Hard of Hearing Program. “Now, our voices can be heard.”

It may be years before a clear understanding of the special health needs of this community emerges, but Rochester researchers will be at the forefront of promoting the issue and solving problems.

“This project will put in place effective interventions that will virtually eliminate any cultural or language or communication barriers that the deaf and hard-of-hearing community now face with their health care,” Hurwitz adds. “The results will dramatically improve the quality of life for deaf and hard-of-hearing people today and for future generations.”

Editor’s Note: For more information about upcoming events in the community during Deaf Awareness Week, Sept. 19 to 25, visit: www.rcil.org/daw

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