

Season's Greetings

Healthy Signs



MEDICINE of THE HIGHEST ORDER

National Center for Deaf Health Research December 2008

Mission of NCDHR:

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

Members of DHCC wish you a Happy and Healthy Holiday!

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This newsletter was supported by Cooperative Agreement Number U48-DP-000031 from the Centers for Disease Control and Prevention (CDC). The findings and conclusions in this newsletter are those of the author(s) and do not necessarily represent the official position of the CDC.

A New Era in Deaf Health Research! Jess Cuculick



With great enthusiasm, I began my one-year term as the chair of the Deaf Health Community

Committee (DHCC). I look forward to representing DHCC as a collaborative partner of NCDHR.

When the Congress in 1986 created Preventive Research Centers (PRC) program, it made a lot of sense to bring academic research knowledge and community living experience together with a common goal: To promote community health and prevent disease. Each and every PRC in the country has a community committee that is an integral part of their community-

based participatory research endeavors.

The collaboration between an academic health center and the community creates a synergic effect, especially when applied public health research focuses on minority communities. In other words, academic researchers are quite knowledgeable about finding ways to promote healthy living, however, by working side-by-side with minority community members, new programs can become much more effective when they are designed to be culturally and linguistically appropriate.

This is now an exciting time in the field of Deaf Health Research. For the first time ever, NCDHR has collected new data

on health status from the Deaf community through its Deaf Health Survey. These new data will guide us in the future to new interventions and studies specifically designed for the Deaf community who communicates in ASL.

I would strongly encourage each and every one of you to spread the word to your family, friends and co-workers about being a part of this excitement here at NCDHR. There are so many ways to become involved, ranging from being a member of DHCC to participating in a research study.

Please feel free to contact us for more information and Happy Holidays to all of you!

Why Collaborate? Tom Pearson



I wholeheartedly agree with Jess' comments above. The word, "collaborate," simply means working together. However, by pooling expertise, experiences, perspectives and awareness, the result becomes much more valuable and meaningful. For example, the Deaf Health Survey is an ideal example of collaboration between researchers and community partners. Collaboration is the key ingredient for a successful community-based participatory research (CBPR) outcome.

More and more academic health centers throughout the country are realizing the enormous benefits of engaging the community - to empower the community to become partners. This is especially true for minority communities. In the past, community people of varying racial and ethnic backgrounds had very little opportunity to become partners in community health research. Now, things are changing. CBPR is opening eyes everywhere. NCDHR is fortunate to have the most exceptional community partner in the country, possibly in the world! That's the Deaf Health Community Committee! This is why I have been advocating for our community leaders to "listen" to Deaf people and engage them in community-wide endeavors to make Rochester one of the

healthiest communities in the country.

The Center for Community Health (CCH), which was just recently formed, will have an important role in bringing together community leaders representing Rochesterians of varied racial and ethnic backgrounds and Medical Center leaders including health researchers. I'm excited that CCH has recognized the Rochester Deaf Community as a new partner! **Jess Cuculick** and **Matthew Starr** gave an enlightening presentation to the Community Advisory Board (CAB) of the CCH, emphasizing that the ASL community must have the opportunity to participate fully in community health endeavors. The CAB includes leaders in health care, health insurance and local government and they will appreciate that the best health policy or intervention is the one that is accessible for all, including Deaf Rochesterians. This type of collaboration will serve as a strong model for communities throughout the country to replicate. The time to fully engage the Deaf community as our community partners is now.

I wish all of you very happy and healthy holidays. I look forward to collaborating with DHCC and with all of you as NCDHR becomes a Center of Excellence for health promotion and disease prevention in the ASL Community.

NCDHR Happenings



Tiffany Panko has been hired by NCDHR as a Transcriptionist. The transcriptionist will view digital video clips of conversations conducted in sign language and produces an English language translation that reflects the original conversations. The transcripts are used by NCDHR researchers to conduct qualitative analysis. Welcome, Tiffany!



NCDHR participated an opportunity to showcase its strong community engagement practices at the September 25 "The Community Engagement Regional Workshop" sponsored by the Association For Prevention Teaching and Research at Weill Cornell Medical

College in New York City. **Matthew Starr** and **Susan Demers** represented NCDHR at this workshop, providing yet another valuable exposure to researchers and community leaders that Deaf citizens are a linguistic minority that has been overlooked by public health research organizations. Dr. Eduardo Simoes, Director of the national PRC Program, was one of the presenters at this workshop and had proudly introduced NCDHR as one role models in engaging the community!



NCDHR's newest (and improved) website has been launched! The website is expected to expand to include a wealth of Deaf Health information. Check out www.urmc.edu/ncdhr! Feedback would

be greatly appreciated!



This month, **Steve Barnett** and **Deirdre Schlehofer** attended the CAHPS Conference in Scottsdale, AZ. CAHPS means "Consumer Assessment of Healthcare Providers and Systems." CAHPS uses surveys to measure patients' experiences at the doctors' office. Many deaf people say they have trouble communicating with their doctor. A CAHPS survey in sign language will give doctors information so they can solve communication problems. NCDHR's Translation Working Groups (TWG) are translating CAHPS questions. NCDHR plans focus groups and survey testing in 2009.

Collaborating with Prevention Research Centers

Michael McKee

The National Center for Deaf Health Research (NCDHR) greatly values collaboration since it allows us to become more successful in achieving our mission of focusing on and resolving Deaf health issues. Collaboration is greatly encouraged by the Centers of Disease Control and Prevention (CDC) since it allows each center to be able to share their strengths and improving each center's efficiency and effectiveness.

As mentioned in the earlier newsletter, Deaf Perceptions is one of NCDHR's projects that evaluates qualitatively the views held by Deaf individuals on cardiovascular health and risk reduction behaviors. The Deaf Perceptions project is also trying to build a collaboration among different Preventive Research Center (PRC) locations across the country. After completing 4 focus groups in Rochester area, our team hopes to be able to replicate the same number of focus groups in at least 2, possibly 3 other PRCs. At this time, we are working closely with

PRCs at University of Colorado Denver (UC) and University of North Carolina at Chapel Hill (UNC). Both have extensive community research experience. By tapping into their community networks, we hope to establish strong contacts with the local Deaf leaders in order to better recruit Deaf individuals for our future focus groups. These focus groups will be conducted in the same way as we handled the focus groups in Rochester. We are excited about the opportunity to work closely with their PRC directors, whom have strongly advocated and supported collaboration with NCDHR. By achieving this collaboration, we hope to be able to learn more about the views held by Deaf individuals on cardiovascular health and risk reduction behaviors at other locations across America. This will allow us to get a better sample and feel for the variety of views the Deaf community may have on cardiovascular health. It will also permit us to see if there are any similarities or differences among each Deaf community studied.

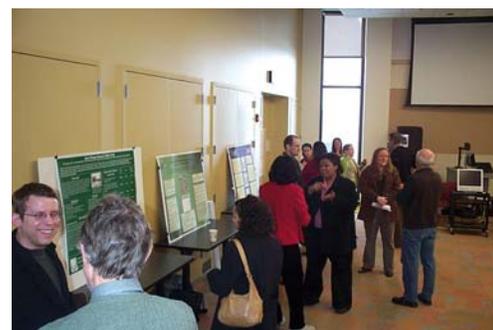
Sharing Research Information Through a "Poster Presentation"

Matthew Starr

Presenting a poster is one way to disseminate (to spread) research information informally to more people. A poster is usually a 36 "x 56" document which can be created from several software such as QuarkXPress or MS PowerPoint and printed by a large printer (offered through printing services). A well-designed poster should display a title, an introduction to the research question or a problem statement, a brief description of the research method, literature cited, some data, discussion of the findings and acknowledgement of individuals/groups who contributed to the development of the poster's contents.

Many scientific conferences and academic symposiums include poster session in their programs. For example, at the American Public Health Association conference last October, there were 1,851 poster presentations! Drs. Barnett and McKee presented their poster, "Adaptation of the Behavioral Risk Factor Surveillance System to the Deaf Health Survey." One of the advantages of poster presentations is close interactions

with individuals who are interested in the research topic presented. With close interactions, the presenters can answer questions individually, exchange business cards for networking and receive feedback instantaneously.



NTID hosted "Deaf Health Research Poster Session," in 2007 (see photo). Eleven posters highlighted the research conducted by NCDHR researchers and community partners. These posters are now on display in the hallways at NCDHR (120 Corporate Woods) or you can view them in the NCDHR Website (www.urmc.edu/ncdhr).