Healthy Signs
National Center for Deaf Health Research
Rochester Prevention Research Center
June 2014

Deaf Health Survey 2013
The clock is ticking!
Take the survey today!

HL2
HL2 and the accomplishments to date: Part 2

DHCC
DHCC Recent Events

NCDHR Happenings
URMC Diversity Conference:
Lori DeWindt reports on NCDHR’s Contributions

COMMUNITY ENGAGEMENT
Farm Stand at the Rochester Recreational Club for the Deaf:
Coming soon!
Deaf Health Survey 2013
The clock is ticking! Take the survey today!

Did you know that we are less than 100 surveys away from completing the Deaf Health Survey? If you have already taken the survey—THANK YOU! If not, what's stopping you? Help your community learn more about its health!

The Deaf Health survey is available on our touch-screen laptops and can be taken in ASL or written English. The Deaf Health Survey can take anywhere from 20-45 minutes of your time. Free parking is provided if you take the survey at our NCDHR offices.

Invite us to your next club meeting or organizational event!

Watch a short vlog about the survey by clicking on the image below.

We can tell your group more about the survey, and invite your members to take the survey.

Get started by contacting Kelly Matthews at:
Kelly_Matthews@URMC.Rochester.edu
(585) 512-8519 VP.
Healthy Living with Hearing Loss, HL2, is a diverse group focused on a common theme; to better understand health issues facing a minority and underserved group of people with hearing loss as a major public health and health care concern.

The March HL2 article, provided an introduction and noted that HL2 is a group of people with and without hearing loss, their family members and those who work with people with hearing loss. HL2 includes community-based organizations such as HLAA-Rochester Chapter; healthcare systems; healthcare professionals, employers; and educators. HL2 members range from 30 to 80 years old. Most use hearing aids and benefit from assistive listening devices, ALDs.

It is important to note that hearing loss is the most common disability in the United States. It is often referred to as an invisible disability impacting an estimated 48 million Americans. About 17 percent of adults in the U.S. report some degree of hearing loss as compared to 1.4 percent that has a physical impairment.

HL2’s major accomplishment to date is the completion of a Summary Report dated September 23, 2013, coauthored by HL2 Members Mary Chizuk, RN, M.S. Ed., Co-Chairperson; Donald W. Bataille, AIA, CCS, Co-Chairperson; Elise de Papp, M.D.; and Basya Herbert, M.D., and coordinated by Steve Barnett, MD and Erika Sutter, MPH, Rochester Prevention Research Center, RPRC, University of Rochester, U of R.

HL2’s initial challenge was to define HL2 as a group. The process of developing a Summary Report validated that HL2 members were in fact the experts, and provided confidence and conviction to move forward and galvanize a vision. The group established the goal: To address the knowledge gaps, disparities and priorities related to people with hearing loss and health by pursuing research opportunities.

The Summary Report was developed through a work process that involved Community Based Participatory Research, CBPR, in partnership with the RPRC, U of R, to better understand health issues facing people with hearing loss through research. This was aided by RPRC with the use of meeting space, support staff to facilitate meetings and maintain minutes and most importantly the moral support to do more.

Through 2010-2011, members continued to meet to discuss:

- Their health concerns secondary to suboptimal communication with their health care providers,
- Affordability of hearing health care including hearing aids and other assistive listening devices, ALDs,
- The health needs of people with hearing loss, as representatives of a minority (part of a population differing from others in some characteristics and often subjected to differential treatment) underserved group and
- The relationship of hearing-related intervention, including hearing aids, with the health of people with hearing loss and their families.

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HL2 initiated distribution of a community wide questionnaire resulting in a listing of more than 90 health concern responses from people with hearing loss, ranging from deaf to mild hearing loss. HL2 members reviewed the list of responses through a process of open dialogue discussions at scheduled monthly meetings. Dr. Steve Barnett, a consultant and a leader in health research with deaf people and people with hearing loss, aided the discussion process. HL2 reviewed the data and created a condensed list of (18) candidate health priority topics.

HL2 members then rated each topic on a scale of 1-10 on two different scales. One scale related to the topic’s importance. A second scale related to the likelihood the topic could be addressed/accomplished in a research study. Utilizing an online survey, REDCap, maintained by RPRC, HL2 members established (9) topics with high importance and high likelihood for success.

The nine HL2 health research priorities were then grouped into five general categories as noted:

1. **Healthcare**
   a. Hearing Loss & Healthcare Communication
   b. Clinicians who are aware of the needs of people with hearing loss.

2. **Mental Health**
   a. Hearing Loss & Anxiety
   b. Hearing Loss & Frustration/Anger
   c. Hearing Loss & Depression

3. **Audiology**
   a. Hearing Loss treatment & overall health/well-being

4. **Cognition**
   a. Hearing Loss & Cognition

5. **Social**
   a. Hearing Loss & Ability to Work
   b. Hearing Loss & Interpersonal Relationships (includes family)

HL2 continued discussion and made the following recommendations:

- HL2 members and NCDHR will work with other stakeholders to broadly disseminate our health research priority topics.
- HL2 members and NCDHR will work with other stakeholders to identify potential funders and develop research proposals to begin to address the health research priorities reported here.
- HL2 and NCDHR will continue CBPR community participatory based research programs.
- HL2 will continue to develop more fully recruit additional members of interest.
- HL2 will identify their research plans to affect public policy by evidence based research.

HL2 continues to meet monthly, in concert with RPRC to match Summary Report findings and recommendations to perspective funding and research programs. If you are interested in joining HL2 please contact Jamie Marsden at Jamie_Marsden@urmc.rochester.edu.
The Deaf Health Community Committee’s 2nd Finger Lakes Deaf Health Fair was a big success! Over 300 people (attendees, interpreters, presenters, exhibitors and volunteers) came to our 2nd Finger Lakes Deaf Health Fair last April 28, 2014. If you were there, see if you can find yourself in those photos on Facebook:

DHCC is deeply grateful to everybody who made this fair a success. Thank you!

2014 Finger Lakes Deaf Health Fair

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May 2014 Deaf Health Talk - Cancer

At the Deaf Health Talk hosted by DHCC on May 15, registered nurse Lauren Searls gave a presentation in ASL about the importance of getting screened for various forms of cancer, especially if one is age 50 or older. Lauren works at the Wilmot Cancer Institute at Strong Memorial Hospital. Nearly 20 community members appreciated having their questions answered in their preferred language. Many thanks to Lauren for taking time from her busy schedule to deliver an important health topic! Thanks also to our partner NCDHR for providing interpreters to make the event accessible for DeafBlind attendees.

Watch our Facebook Page for information on our next Deaf Health Talk, a program of the Deaf Health Community Committee and Rochester Recreational Club for the Deaf’s (RRCD) R.E.A.P. (Rochester Educational Awareness program). To find us on Facebook, click on the “Like” image above.

Lauren Searls gives a presentation in ASL at the Rochester Recreational Club for the Deaf
URMC Diversity Conference

Lori DeWindt reports on NCDHR’s contributions

In March, the University of Rochester Medical Center (URMC) had its Diversity Conference on March 28th, 2014. The day long event theme was “Crossroads: An opportunity for Progress”. The event was used as a way to stimulate the dialogue of race and power. This dialogue prompted the greater efforts to redefine diversity. The event welcomed many people from different walks of life including community members, administrators, staff and students. NCDHR was selected for an hour long presentation. NCDHR’s workshop appropriately reflected the theme of Diversity. “Embracing Deaf, American Sign Language (ASL) and Hearing Loss as unique Assets of the Rochester Deaf Community.”

Strengthening diversity awareness is necessary as Rochester is home to a large population of Deaf people and people with hearing loss. The workshop focused on the basic principles of human rights and respect for all people. During the workshop, we acknowledged that Deaf people and people with hearing loss are unique with strengths that can make a positive effect on University of Rochester because we have engineers, nurses, cashiers and doctors of many disciplines who are Deaf and have hearing loss. The focus was to explore how research, healthcare, education and employment can open doors to many Deaf people and people with hearing loss. The workshop was geared for people to gain practical and personal experience to support them and their department to include deaf and hearing loss students, colleagues, patients, participants and consumers.

The audience members gained practical information during an interactive workshop with hands on experience on how to communicate and work effectively with this unique community. The stimulated scenarios were discussed and it was a great opportunity to see participants advocate for others and begin to challenge themselves to think differently.

The presenters were Lori DeWindt, Kelly Matthews and Jackie Pransky. They were able to share the experience and to facilitate the workshop. More information on Diversity can be found on http://www.rochester.edu/diversity/annualconference/2014/index.html

Click on link above or the image to the left to see the keynote and more information about the Diversity Conference.

The opening keynote is interpreted and captioned.
Farm Stand at the Rochester Recreational Club for the Deaf

Coming soon!

NCDHR will work with the Rochester Recreation Club for the Deaf (RRCD) to host Foodlink’s Farm Stand for the third year in a row. Last year, in the summer of 2013, the Farm Stand at the RRCD distributed over 3,000 pounds of fresh, local and affordable produce to the deaf community and the club’s surrounding neighborhood.

We hope that 2014 will be a successful year for us! This year’s Farm Stand will take place every Saturday from 10am-1pm starting Saturday July 12th - Saturday, September 6th. This is hosted at the Rochester Recreation Club for the Deaf at 1564 Lyell Ave - Rochester, NY 14606.

CALL FOR VOLUNTEERS: We would not be able to successfully run this Farm Stand without the help from volunteers. What would you be doing as a volunteer? Examples: setting up tables, arranging produce for sale, setting prices, assisting stand visitors and handling cash transactions. We usually have three to five volunteers each Saturday. If you would like to become a volunteer for the Farm Stand at the RRCD, please contact Kelly at Kelly_Matthews@urmc.rochester.edu or (585) 512-8519 VP.

Please stay tuned for more information regarding Cooking Demonstrations and overlapping events from the RRCD (Garage Sales, BBQ, etc.).

Click here to view slideshow.

The Farm Stand is an initiative within H.E.A.R.T. (Health Engagement and Action for Rochester’s Transformation). This will be the third year of the partnership between NCDHR, Foodlink and the Rochester Recreation Club for the Deaf (RRCD).
Mission of NCDHR: To promote health and prevent disease in the Deaf and hard of hearing populations through community-based participatory research.