

# Healthy Signs

National Center for Deaf Health Research May 2013

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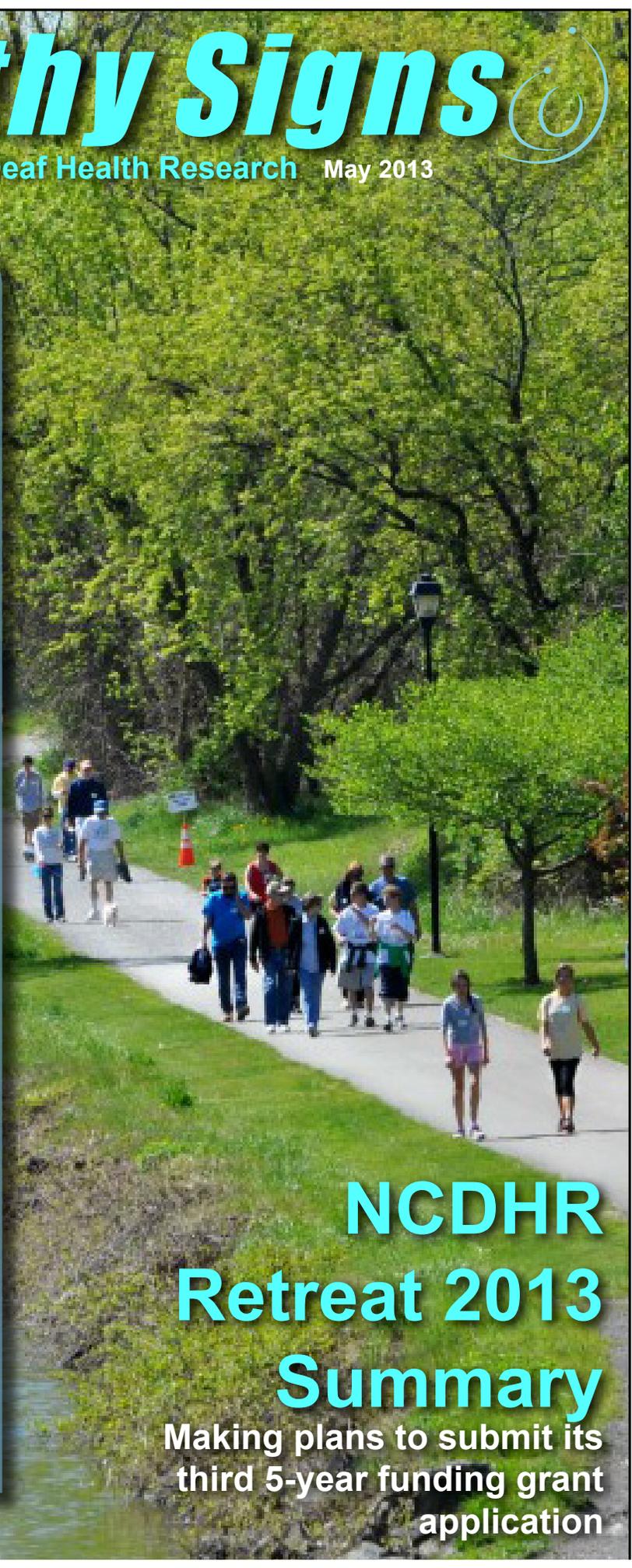
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Deaf Mothers' Outreach in Support of Breastfeeding - The production of Vlogs

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## Where are they now?

Susan Demers-McLetchie



## NCDHR Retreat 2013 Summary

Making plans to submit its third 5-year funding grant application

## NCDHR Retreat 2013 Summary

### Making plans to submit its third 5-year funding grant application

As the second 5-year Prevention Research Centers (PRC) funding is approaching its last year (October 2014), our center and its community partners are gearing up for a busy time to apply for its third funding cycle. It's expected that the 2014-2019 PRC application (called "Funding Opportunity Announcement" or "FOA") will be released sometime this summer, with a submission due date a couple of months later. Typically, universities would delegate some of its faculty to write the grant application, which sometimes can be hundreds of pages long! However, the PRC's FOA requires an university to demonstrate clear evidence of collaboration with its community partners. The centerpiece of the PRC program is "Community-Based Participatory Research (CBPR)." The definition of CBPR is:

*"A collaborative process of research that involve researchers and community partners in **all phases of research.**"*

Preparing for a new public health research grant application is considered an important phase of research. This preparation involves:

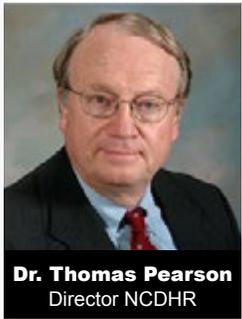
- *Analyzing past and current health data*
- *Identifying health priorities*
- *Determining the feasibility of proposed research ideas*
- *And much more*

It also requires the involvement of both researchers and community partners – just as in the above highlighted part of the definition.

Our center is interested in learning what our community members, who are considered "experts" in their everyday life experiences, think about which issues would have the greatest community health benefit(s) for their communities. Our Rochester PRC (NCDHR) has successfully secured 5-year funding grants in 2004 (to develop an ASL-based Deaf Health Survey) and in 2009 (to study a randomized clinical trial of a healthy lifestyle intervention called "Deaf Weight Wise"). As for the 3rd funding cycle, how can both researchers and community partners decide what the core research project should be? The process of narrowing down numerous issues into a prioritized "research core project" is a major undertaking, and this process has just begun with the first center-wide retreat last month.

*How can both researchers and community partners decide what the core research project should be?*

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**Dr. Thomas Pearson**  
Director NCDHR



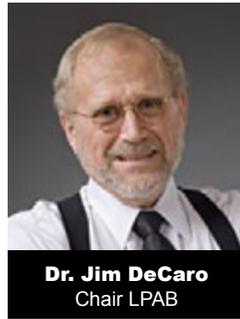
**Val Nelson-Metlay**  
Chair DHCC



**Mary Chizuk**  
Co-Chair HL2



**Don Bataille**  
Co-Chair HL2



**Dr. Jim DeCaro**  
Chair LPAB



**Matt Starr**  
Administrator NCDHR

Nearly 40 researchers and community partners met during the evening at the Saunders Research Building on April 3. An [agenda](#) and communication, participation & courtesy [ground rules](#) were distributed. Retreat participants enjoyed dinner during introductions to staff and volunteers announced by chairs of various committees: Dr. Thomas Pearson for NCDHR, Valerie Nelson-Metlay for the Deaf Health Community Committee (DHCC), Mary Chizuk and Don Bataille for the Healthy Living with Hearing Loss (HL2), Dr. Jim DeCaro for the Local Partner Advisory Board (LPAB) and Matt Starr for other partners such as NCDHR's Community Partner Staff.

After the introductions, Dr. Pearson gave an engaging [presentation](#) about NCDHR past and current accomplishments in five significant center components: infrastructure, research, community partnerships, communication & dissemination, and education & training.

Then, Drs. Jim DeCaro and Scot Atkins, both from NTID, served as effective facilitators for further discussions on three questions: (1) How are we doing?, (2) What should the next step be?, and (3) Who else should be involved?



**Dr. Scot Atkins**

Numerous comments were recorded from the retreat participants. [Click here](#) to see the summaries of the retreat comments. Many thanks to Jim and Scot for a job well-done in engaging and facilitating retreat participants' thoughts and comments!

In closing, Dr. Pearson wrapped up by explaining the timeline for this year's FOA process. Matthew Starr, Administrator and Community Liaison with the Rochester PRC, will be working closely with leaders from all community partners to plan and organize town hall meetings, within the next two months. These meetings will be open to the Deaf community as well as to the community of people with hearing loss.

Stay tuned!



*No one should be left out during any community-based deliberations on what should be the most important community health issue or issues, especially for Deaf ASL users and people with hearing loss!*



To see the PowerPoint presentation from Dr. Thomas Pearson during the retreat, click on the image above.

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Where are they now?

Finger Lakes Deaf Health Fair  
A summary and recap

On April 20th, the Deaf Health Community Committee (DHCC) held their first Finger Lakes Deaf Health Fair at the Rochester School for the Deaf. NCDHR was thrilled to be a part of this event, providing an exhibit table with information related to current and upcoming research events.



NCDHR staff provided information about the upcoming Deaf Health Survey 2013 and also had our [recruitment](#) video on display, explaining why the Deaf Health Survey is being held again and the importance of the community involvement with research.

As part of the Health Engagement and Action for Rochester's Transformation (HEART) initiatives, NCDHR also promoted the [Deaf Farm Stand](#), which will resume again



in July at the Rochester Recreation Club for the Deaf. NCDHR was successful in recruiting 14 community members to be a part of this project as volunteers.

The Finger Lakes Deaf Health Fair brought both new and familiar faces to NCDHR's table. Some who have been a part of NCDHR's research since it began, and some out of town or out of state individuals who were not familiar with NCDHR but were eager to learn more about Deaf Health Research. Roughly 65 people approached the NCDHR table to learn more.



During the entire day's events, more than 200 attendees participated in the Finger Lakes Deaf Health Fair. Many people remarked that it was an enriching experience in learning about Deaf culture, its language, American Sign Language (ASL), blended with healthcare and healthy lifestyle education.

Of course, the success of the health fair would not be possible without the participation of the health fair partners, including over 20 health-related organizations and the Rochester School for the Deaf. Additionally, Genesee Valley Region Registry of Interpreters for the Deaf (GVERRID) was a co-sponsor of the event.

If you have any afterthoughts on how the Finger Lakes Deaf Health Fair Planning Committee can even do better for the next Deaf Health Fair, please do not hesitate to contact them at: [FLDeafHealthFair@gmail.com](mailto:FLDeafHealthFair@gmail.com).

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Where are they now?

## Walk4Hearing

### HLAA - Helping those with Hearing Loss

By David Koon

Article from the Genesee Valley Penny Saver

Photos provided by Arthur Maurer

Did you know that more than 36 million people in the US have a hearing loss which can hinder daily communication? By age 65, one in three Americans has a hearing loss. When hearing loss occurs suddenly there is no denying it; the world and your life change immediately. When hearing loss occurs over years, the changes in your life are not as clear-cut. It's easier to tell yourself it's not really your hearing, it's that people "mumble" or are "talking too fast," or "I was distracted, so I missed what you said."



David Koon, 2013 Walk Chairperson, and Sue Miller, 2012 Chairperson

Admitting you have a hearing loss is the first step; having your hearing tested by your doctor or an audiologist is the next. People respond differently to the news that their hearing loss is real and they need help, usually by the use of hearing aids. If your hearing loss is mild, the transition may be relatively easy; if it's severe, the adjustment may take longer. Once your hearing loss is confirmed you may feel vulnerable or depressed. Rest assured you are not alone. Everyone with hearing loss has experienced various degrees of anxiety and uncertainty. As you gain knowledge and experience you will gain courage and confidence. You'll learn to enjoy life despite your hearing loss. Now is the time to gather information, seek help from others and develop a plan of action.

The Hearing Loss Association of America can help. Their mission is "to open the world of communication to people with hearing loss through advocacy, information, education and support." The Rochester Chapter was established in 1983 to help people in western New York who are living with hearing loss. You'll find a wealth of information on their website: <http://www.hlaa-rochester-ny.org> or call 266-7890; an award winning monthly newsletter is also available.



Start of the 5K Walk

The group meets the first Tuesday of the month (Sept.-June) in the Vestry Room at St. Paul's Episcopal Church, located at the corner of East Ave. and Westminster Rd. in Rochester. All meetings are audio looped and captioned. HLAA Rochester strives to keep its members informed about issues that are important to the hearing loss community. Recent meetings have included discussions of the latest hearing aid technology, advances in cell phone technology, rights under the American with Disability Act, and question and answer sessions with local audiologists. The organization also funds captioning of live theater performances.

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Helping people to feel less isolated and encouraging them to get the best possible services and technology available to enrich their lives is central to the mission of HLAA Rochester. As member Cindy Kellner says, "HLAA made me aware of so many options and helped me to realize I was not alone. The volunteers were so knowledgeable and enthusiastic."



Along the scenic Erie Canal towpath

The [Walk4Hearing](#) is the main fundraiser for HLAA Rochester. Funds are used to provide scholarships towards college tuition for students with hearing loss, to pay for captions and assistive technology used at chapter meetings, to help fund hearing devices for people who cannot afford them, for seminars on coping with hearing loss, and for installing a hearing loop system in the Dryden Theater at the George Eastman House.

Walk4Hearing took place recently, May 5, 2013 at Perinton Park in Fairport, along the Erie Canal. There was fun for all ages: breakfast, clowns, face painting, music, and a silent auction full of great gift cards and other goodies from local merchants.

This year organizers have set a goal to raise over \$55,000. Businesses were invited to sponsor and/or donate items for the Silent Auction. The day was beautiful and many walkers showed to support the HLAA. Thank you to all who participated and gave donations to the Walk4Hearing.



One of the many Walk4Hearing teams



A clown painting a young walker's face; one of the many fun activities provided throughout the day.

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**Where are they now?**

## Upcoming Events!

### External Advisory Committee (EAC) 2013: June 18-19



Every year, NCDHR hosts an annual meeting for the NCDHR External Advisory Committee (EAC). Members of the EAC include nationally prominent individuals with strong experience and commitment to health promotion for Deaf people and for people with hearing loss. The EAC provides guidance and feedback incorporating a national perspective on NCDHR's strategies and goals. NCDHR looks forward to welcoming them from across the country during the upcoming EAC meeting.

### 5th Annual Rochester Deaf Festival 2013: June 8

Come to the 5th Annual Rochester Deaf Festival, on Saturday, June 8, to see all your friends from NCDHR, the Deaf Health Community Committee (DHCC), and many other vendors.

There will be many activities and lots of entertainment throughout the day.

NCDHR will be revealing a new study!



For more information on the festival, go to [www.rochesterdeaffestival.org](http://www.rochesterdeaffestival.org)

**FREE Admission & Everyone Welcome!**

**NEW LOCATION!**

5th ANNUAL **Deaf Festival** 2013  
ROCHESTER, NY

**June 8, 2013 SATURDAY**  
**11:00 am to 4:00 pm**

- Many Vendors
- Entertainment
- Refreshments & Much More!

at Genesee Valley Park  
Elmwood Ave, Rochester, NY 14620

[rochesterdeaffestival.org](http://rochesterdeaffestival.org)



Scan this code onto your smartphone for more info!

501(c)(3) certified non-profit organization



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## Matt Starr Lectures at St. John Fisher College

The goals of Rochester Prevention Research Center are not limited to community-based participatory research with the deaf and hard-of-hearing communities, but also to offer expertise and training in cultural competency to healthcare workers locally and nationally. Dr. Jennifer Mathews, Assistant Professor from the Wegmans School of Pharmacy at St. John Fisher College, acknowledged that Rochester is the home of one of the largest concentrations of deaf and hard-of-hearing people in the country. She felt that it was especially important for future pharmacists to become aware of these populations when they start serving them in pharmacies. Earlier this year, she invited Matthew Starr, MPH to present, "Interacting with people who are Deaf or have hearing loss," to nearly 75 first-year pharmaceutical students on March 20 as a part of their coursework, "Introduction to



Diversity." The take-home message that Matt Starr emphasized was that Deaf people and people with hearing loss are not homogeneous, but each subgroup has very different communication needs and are culturally distinctive. The presentation was well received and many thanks goes to Dr. Mathews in ensuring that future pharmacists become better informed when working with people who are Deaf or have a hearing loss.

## Deaf Mothers' Outreach in Support of Breastfeeding: The production of Vlogs

Last November, Jessica Cuculick, past chair of the Deaf Health Community Committee (DHCC), presented some work at the American Public Health Association national conference in San Francisco. In a session on technology and breastfeeding, Jess introduced a vlog project to a national audience of breastfeeding researchers. Rochester breastfeeding researchers (Cuculick, Nancy Chin, and Ann Dozier) hypothesized that the characteristics of Deaf culture and signed languages uniquely support breastfeeding in this community. Members of the Rochester Deaf Moms Club (RDMC) told researchers that there are deaf mothers in the US isolated from Deaf community support and breastfeeding information for hearing mothers is not accessible for them. Deaf Moms and researchers worked together on the production of vlogs (video blogs) which could provide language accessible support for deaf mothers around the US. Six deaf mothers generated vlog topics. Topics

were informed by deaf cultural norms of using stories and scenarios to illustrate the social and logistical advantages of breastfeeding. NCDHR staff interpreter, Kim Kelstone, was a critical member of the production team: she edited all the vlogs and taped many of them. Many thanks goes to NTID student, Melissa Kielbus, who volunteered with the project to tape some of the initial vlogs.

Why vlogs? They are free, easy, accessible, and VISUAL. Topics included how long women breastfeed; to establish breastfeeding as normative; and how women garnered family support for breastfeeding. At the presentation, Jessica carefully pointed out that the success of the project was due to active community participation of Deaf Mothers. "Everyone," she told the audience, "approaches minority communities looking for problems or deficits. Our community-based participatory project highlighted the strengths of the Deaf community and the assets they bring to the national discussion on how to get more mothers in the US – deaf and hearing – to breastfeed."

## 2013 University of Rochester Diversity Conference Our Differences Our Strength

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Picture provided by [www.rochester.edu/diversity/annual conference/2013/](http://www.rochester.edu/diversity/annual%20conference/2013/)

On Friday, April 12, 2013, the National Center for Deaf Health Research (NCDHR) presented “Welcoming Deaf and Hard-of-Hearing People in Research, Treatment, Work, and Education” at the Fourth Annual University of Rochester Diversity Conference. This workshop emphasized inclusion of diversity in the deaf/hard-of-hearing communities through different ways.

Lisa Lowenstein led the workshop, clarifying myths such as ‘everyone who is deaf knows sign language’ or ‘hearing aids and cochlear implants will fully restore hearing to normal’ or ‘people who can’t hear can’t use the telephone’. Not everyone who is deaf or hard-of-hearing knows American Sign Language (ASL). In fact, within both communities, there is a variety of communication preferences; ASL, Signed English, Cued-speech, and spoken language and lip reading, among others. Assistive listening devices (such as hearing aids and cochlear implants) do not completely restore hearing. The benefits of these devices range, depending on the individual, to nearly complete hearing to environmental awareness to minimal or no benefit. People who are deaf and hard-of-hearing are not isolated from the world around them. With new technology developments (videophones, texting, Facetime, Skype, captioned phones, etc), deaf and hard-of-hearing people are more connected to the world around them than ever before. Many of these myths were discussed and clarified. For the full powerpoint presentation, [click here](#).

Jackie Pransky continued the workshop by explaining the transition in history from viewing the deaf population with a medical standpoint to a cultural identity of a minority group. Even within the deaf and hard-of-hearing communities, deaf and hard of hearing people vary widely in describing themselves. The possible barriers to inclusion are differences in languages and cultures. For example, American Sign Language differs from English on many levels. It is crucial that there is accurate translation to communicate clearly. The deaf community does have their own norms and cultures (much like other minority cultures) that other people may misunderstand in translation.

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Kim Kelstone followed Jackie's presentation with a discussion about support services and how they are a shared responsibility for everyone to make sure that everyone has full access to communication. Kim elaborated using examples of situations that may arise, bringing with them confusions regarding responsibility for support services. Kim provided a list of appropriate organizations to contact who currently provide those services as well as an accommodation cost breakdown. Participants in the workshop were then broken into groups to discuss a variety of scenarios and how they would handle them.

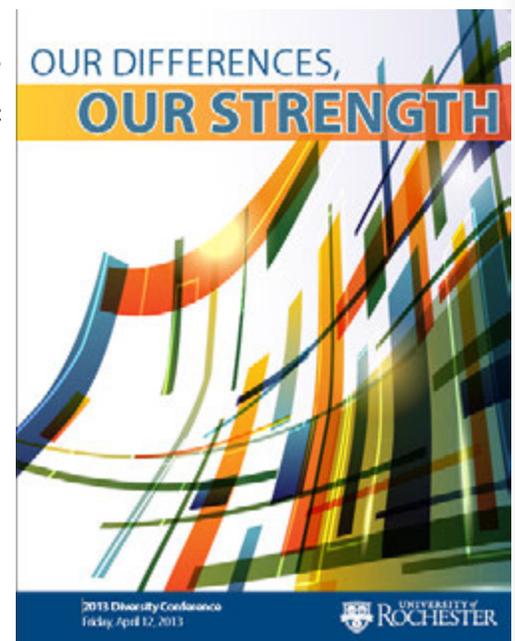
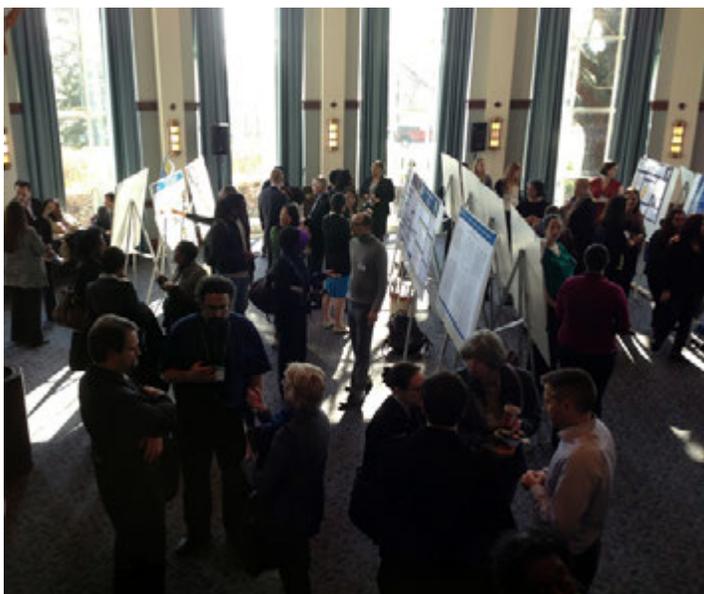
Kelly Matthews ended the workshop by leading a group discussion on how to foster more diversity and inclusion with deaf and hard-of-hearing people at work, especially in research. Deaf and hard-of-hearing people may not use English as a first language and questions in English may not translate correctly to ASL. She suggested hiring community members to aid in community outreach and translation. Kelly shared some scenarios and participants brainstormed ways to include diversity in their everyday lives.

Participants were given the opportunity to comment on the NCDHR workshop they attended. 31 participants commented:

*I found the first workshop that dealt with inclusiveness in the deaf community very useful. As someone engaged in community education and recruitment for clinical trials, it opened my eyes to ways we can better include more communities in our efforts, as well as better serve all people's needs.*

After a long day of workshops, the Diversity Conference was well attended and everyone left with a sense of accomplishment and improvement.

To see the Diversity Conference 2013 program booklet, click on the image to the right



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Where are they now?

## Where are they now? Susan Demers-McLetchie

In October 2010, Susan Demers-McLetchie, the first chair of the Deaf Health Community Committee (DHCC), and past employee of NCDHR, moved to Boston to work for the Massachusetts Commission for the Deaf and Hard of Hearing. During her tenure as the chair of the DHCC, numerous accomplishments and milestones were achieved: building consensus between the Deaf community and researchers, prompting efforts to conduct a first ever qualitative study on identifying partnership barriers/solutions (Rapid Assessment Process), asserting for the creation of the Translation Workgroup (TWG), co-presenting at state-wide CBPR conference, which NCDHR/DHCC was awarded as the “best CBPR paper,” spearheading to enact and complete the Governance Guidelines for the DHCC, and much more.



Nearly 6 years later, “Where is Susan now?” Presently, she is married to Antony McLetchie, Principal of two schools; Ernest C. Drury Secondary School for the Deaf in Milton, Ontario and Robarts School for the Deaf in London, Ontario. She lives in Milton, with two of her teenage children,

Kalika and Kyle, along with an adorable two year old daughter, Rainna, and Tony’s children.

Since Susan left the DHCC and NCDHR, her life has gotten even busier with her current career and family responsibilities. After working for the Commission for the Deaf and Hard of Hearing as a Communication Access Outreach Training Specialist in the Communication Access, Training and Technology Services Department (CATTS) for two years, she got married and moved to Canada. You can see her vlog describing [CATTS here](#). Once in Canada, she had Rainna.

Some of you may recall that Susan was the President of DeafWorks!, which was renamed to “DT Deaf Services & More.” She and her business partner, also continue to provide consultative services, especially job placements. Susan continues to work with Sprint as an independent contractor. Finally, she provides English to ASL translation expertise for the Provincial Schools Branch of the Ontario Ministry of Education. Through a subcontract with Canadian Hearing Society, Susan, as an independent contractor providing ASL Talent and coaching services, and her team are part of an exciting project that is responsible for creating translated sign language videos that would enable Provincial Schools Branch website fully accessible to ASL and LSQ (French Sign Language) users. When asked about her translation work, especially with the TWG, she responded,

*“Being on TWG was awesome and fulfilling. I realized translating from English to ASL was something I really enjoyed doing. It came with a myriad of roles, from researching, analyzing and discussing the language to being in the filming studio as coach. I have continued to do a similar line of work since then. As technology advances each day, this translation work seems to be in high demand here right now trying to make websites more accessible to everyone which is definitely a good thing.”*

(For those of you are interested in reading a published article about TWG, check out: Graybill P, Aggas J, Dean RK, Demers S, Finigan E, Pollard RQ. (2010). [A community participatory approach to adapting survey items for Deaf individuals and American Sign Language](#). Field Methods 2010; 22(4); 429-448.)

Thanks to Susan’s hard work and leadership during NCDHR’s early years, the DHCC remains one of the key community partners with NCDHR. Best of luck to Susan and do keep in touch!



**Mission of NCDHR:** To promote health and prevent disease in the Deaf and hard of hearing populations through community-based participatory research.



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