

# Healthy Signs

National Center for Deaf Health Research January 2013

## COMMUNITY ENGAGEMENT

**Dr. Philip Zazove becomes Chair of Family Medicine**

Dr. Michael McKee becomes the new Director of the Deaf Health Pathway

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## HL2

**Healthy Living with Hearing Loss: A New Community Committee**

See what's happening at NCDHR!

Feb 11,  
Open House  
5:30-7:30pm

Free food  
Free parking  
More details to come

## DHCC Retreats

A Message from  
Val Nelson-Metlay,  
Chair of the DHCC

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## DHCC Retreats

### A message from Val Nelson-Metlay, Chair of the DHCC

The Deaf Health Community Committee (DHCC), a community partner with the NCDHR, decided to “pause” from their busy meeting schedule to take time for reflection and renewal by participating in a retreat. Val Nelson-Metlay shares the reasons for this retreat. . .



Almost every month since 2005, members of the DHCC have participated in numerous research meetings ranging from a presentation by a medical student, sending letters of support for grants, reviewing research manuscripts, and doing participatory data interpretation with the NCDHR researchers. Also, countless hours of discussion about organizational issues, strategic planning and self-governing matters have taken place at subcommittee meetings, coffee houses, public libraries and people’s homes. In addition, many of the DHCC members have participated in workshops, other community-based health councils, traveled out of state for conferences, and represented DHCC at festivals and open houses. All of that time and energy spent was to support the mission of DHCC:

***Mission Statement:*** *DHCC is a partnership between Deaf communities, researchers, and health providers to promote the understanding of the health needs of culturally Deaf people (American Sign Language users), to identify issues essential to creating parity (to become equal) between the Deaf and general (hearing) population, across the nation.*

The spirit of Community-Based Participatory Research (CBPR) is what drives the partnership. In simple terms, CBPR is a collaboration between an academic health center and the community to seek effective ways to improve the health of the community. DHCC is a self governing body of 18-25 people, of whom more than half are Deaf American Sign Language (ASL) users and they represent the Rochester Deaf Community. Most of our members are not academic researchers, but they bring a wealth of experiences and knowledge as members of the Deaf World to NCDHR. Both DHCC and NCDHR have been awarded for outstanding collaborative efforts, starting with a “best-written” paper for a community-academic conference in Binghamton, NY in 2006 to Community Partnership Engagement Award in 2010, presented by the National Community Committee of the CDC’s Prevention Research Center Program.

As NCDHR grew, DHCC’s level of need to serve as a stronger community partner has become greater. The need to evaluate how the DHCC can become a more effective partner became a priority. That was when the idea for a retreat emerged.

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## DHCC Retreats



During the first retreat, last spring at the Chili Public Library, DHCC members first enjoyed a humorous icebreaker (what was your most embarrassing moment?). Then, discussion followed about what were the members' expectations of their organization, (what is DHCC and what is not DHCC?). Alicia Lane-Outlaw, a DHCC member, facilitated a SWOT (Strengths, Weaknesses, Opportunities, and Threats) session. The retreat was a terrific opportunity for the DHCC members to re-evaluate our organization and to determine whether our actions, comments, thoughts, discussions, and planning were aligned with its mission. Most importantly, did our actions and results benefit the Deaf community? As a result, nearly 80 SWOT comments were proposed!

During the 2nd retreat, held last May 1 at my (Val Nelson-Metlay's) home, DHCC members had the huge task of reviewing the SWOT comments and prioritizing them. Because there were so many comments, we had to post them on all four walls in the dining room! After much well thought out deliberations (a delicious potluck dinner helped with our thought processes), the top 5 challenging issues emerged:

1. Not everyone in the local Deaf Community knows what DHCC is;
2. Deaf filmmakers have limited opportunities to create "eye-catching" ASL videos for health and research promotions;
3. Job openings and/or request for specific skills needs to be more widely advertised;
4. ASL-English discourses, especially when academic health and Deaf community partners communicate with each other, with and without interpreters, have not always been effective;
5. The Rochester (NY) Deaf Community does not have a broad community-based Deaf service/advocacy center.

On May 30, the DHCC then met with the NCDHR Director/Principal Investigator, Dr. Thomas Pearson, to discuss the above issues. After a frank and fruitful discussion, Dr. Pearson and the DHCC leadership announced that this was an excellent meeting with the following action items:

1. DHCC can set up focus groups with members of the Deaf community to learn what works and what doesn't work on how to get the word out about engaging the Deaf Community to DHCC and NCDHR.
2. Include DHCC in all outreach activities. Consider a new name for DHCC (for instance, DHCC is an independent organization, not a committee of NCDHR).
3. DHCC to consider applying for 501(c)(3) status.
4. Any job postings and or requests for specific skills will be sent to DHCC and DHCC can help spread the word to the Deaf Community.
5. DHCC can offer feedback and suggestions on how to improve ASL-English discourse.
6. DHCC will spearhead efforts to establish a broad community-based Deaf service/advocacy program.

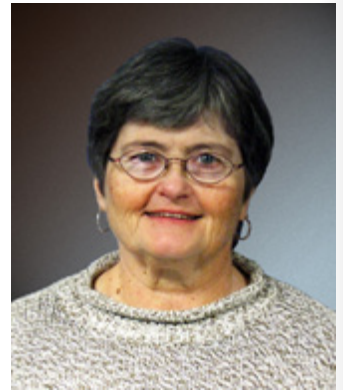
Patrick Graybill, DHCC past Chair, signed, "TAP (Thomas Pearson) listened to our concerns very well. DHCC should and will become much more independent and take action without having to wait for NCDHR."

As the current chair of the DHCC, I am excited to have this opportunity to serve an outstanding group of individuals who are dedicated to collaborating with NCDHR to learn what evidence-based public health can be applied to improve

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## DHCC Retreats

the health of our Deaf community. Our ongoing challenge is to find new ways to reach out to more Deaf people and encourage them to become more involved with their health and the health of their families and communities. Any interested individual wishing to become engaged with DHCC, please contact Matthew Starr at (585) 286-2721 or e-mail at [matthew.starr@urmc.rochester.edu](mailto:matthew.starr@urmc.rochester.edu).



Have a warm and safe winter!  
Val Nelson-Metlay

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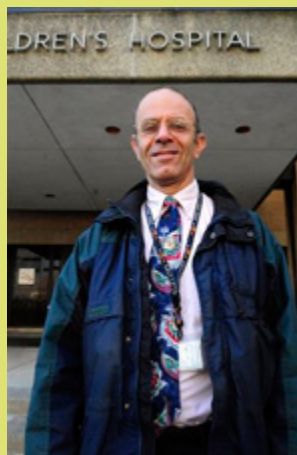
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## Dr. Philip Zazove becomes Chair of Family Medicine at the University of Michigan



Picture compliment of AP  
Photo/The Michigan Daily,  
Jed Moch

Dr. Philip Zazove, a long-time member of the NCDHR's National External Advisory Committee (EAC), was named chair of the University of Michigan Medical School's Department of Family Medicine. Dr. Zazove is a deaf physician who fought the odds to become a doctor and to become the chair of one of the largest Family Medicine departments in the country! He is also author of *When The Phone Rings, My Bed Shakes*, as autobiography about his life as a deaf physician. Working at the University of Michigan, he has several clinical and research interests, which include health services issues of Deaf and Hard of Hearing people, incorporating

genetics into primary care settings, rising health care costs, and continuous quality improvement. Dr. Zazove's second book, heavily involved Deaf Culture, entitled *Four Days In Michigan*, was

released in October 2009. To read more about his achievements, click [here](#).

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## **Dr. Michael McKee becomes the New Director of the Deaf Health Pathway at the University of Rochester**

In November, Dr. Michael McKee, a physician at the University of Rochester Medical Center and a researcher with the National Center for Deaf Health Research, became the Director of the Deaf Health Pathway at the University of Rochester Medical Center.



The Deaf Health Pathway (DHP) began 8 years ago by a student named Vasanth Kainharyam. Vasanth was a linguistics major before medical school and was interested in learning more about American Sign Language (ASL) and Deaf Culture. Vasanth wanted to know more about the health needs of the Deaf Community in Rochester, and with the help of Bob Pollard and Steve Barnett, he created the first courses and activities for the DHP.

Since that time, the DHP has grown and grown. New students continue to participate in the DHP each year, including students such as Heidi Thompson and Chris Chang. Students improve their curriculums and network with Deaf community members, educational institutions, and the National Center for Deaf Health Research.

In need of an ASL fluent Director, the DHP reached out to Dr. McKee. Dr. McKee is personally and professionally connected to the Deaf community and is fully part of the Deaf Culture as well. Previous Director, Dr. Stephanie Brown Clark commented, "I am very happy that Dr. McKee has these connections and talents. I know he will do a fine job."

NCDHR is very proud of Dr. McKee for this recent accomplishment and knows he will be a great addition to the DHP.

# Research Updates from NCDHR

## A Recap of 2012 and what's to come for 2013

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### Deaf Weight Wise: A Healthy Lifestyle Program for Deaf ASL Users

**Principal Investigator:** Thomas A. Pearson, MD, MPH, PhD



**Purpose of Project:** Deaf Weight Wise (DWW) is a clinical trial of a healthy lifestyle program for Deaf ASL users. Participants are ages 40-70, with a Body Mass Index (BMI) of 25 to 45. The 16-week program includes group discussion, problem solving, group exercise activities, and healthy eating and cooking skills. Small groups of Deaf ASL users meet weekly and are led by a trained Deaf counselor.

**What happened in 2012:** DWW successfully enrolled 104 participants this year. Congratulations to participants who have completed their 16-week group program about healthy living, healthy eating, and exercise! The other half of the participants were randomly selected to start their 16-week group program in spring/summer of 2013 – we look forward to the 2013 group meetings.

DWW participants will come to NCDHR every 6 months for ASL surveys and bloodwork appointments, from now until 2014. Those results will help the NCDHR team learn about the health of participants throughout the program, and how the program worked.

At the end of the research program, NCDHR will share the results with the Rochester Deaf community. We look forward to your participation in community meetings to help us understand how the results of DWW will impact the Deaf community. Stay tuned!

### Deaf People and Healthcare



**Principal Investigator:** Steven Barnett, MD

**Purpose of Project:** To learn about the healthcare experiences of deaf people aged 18 and older in Rochester, NY.

**What happened in 2012:** This fall we finished recruiting participants for the Deaf Healthcare Survey – thank you to everyone who helped with this research project! This survey asked important questions about deaf people's experiences with doctor visits including questions about communication and access to healthcare. A total of 102 people took the survey. About half the people who took the survey were men and half were women, and the average age was 46 years old. Now that we have finished collecting data, we will be analyzing the information so that we can share results with the community.

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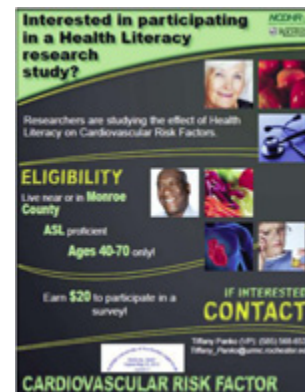
## Research Updates from NCDHR

### Health Literacy Among Deaf ASL Users and Cardiovascular Health Risk

Principal Investigator: Michael McKee, MD, MPH

**Purpose of Project:** To learn more about health literacy and how this can affect cardiovascular health in hearing English speakers and deaf American Sign Language users.

**What happened in 2012:** We had 122 deaf participants and 168 hearing participants take surveys on computers and answered questions related to health literacy and cardiovascular risk factors. The age range is from 40 years to 70 years old. We also collected blood samples to test for total cholesterol and hemoglobin A1C ( to test for diabetes).



**Our goal for 2013:** Our goal for 2013 is have 250 participants for both deaf and hearing groups. To meet this goal, we are seeking 128 more deaf participants to join and 82 more hearing participants. For interested deaf American Sign Language users, they are welcome to contact Jacqueline Pransky at [Jacqueline.Pransky@urmc.rochester.edu](mailto:Jacqueline.Pransky@urmc.rochester.edu) or call **585 568 6534 (VP)** for more information. Hearing English-speakers can contact Martha Tuttle at [Martha.Tuttle@urmc.rochester.edu](mailto:Martha.Tuttle@urmc.rochester.edu) or call **585 506 9484 x120**.



### Assessing Cardiovascular Risks in Deaf Adolescents who use Sign Language

Principal Investigator: Scott Smith, MD, MPH

**Purpose of Project:** To develop a new cardiovascular health literacy survey for young people that captures “fund-of-information” issues that might be more important for deaf than hearing people.

**What happened in 2012:** We have conducted focus groups with young deaf people this year as a first step in the project. A sign language survey is currently being developed, including translation and filming of survey questions. The survey is now being evaluated and refined through back-translation and cognitive interview process. The final survey will be given to a group of young deaf people in the summer of 2013. We also recently completed data collection to pilot test the Short form of Test of Functional Health Literacy in Adults (S-TOFHLA) in approximately 115 deaf college students in order to validate this test for the use with deaf college students.

### Factors Influencing Partner Violence Perpetration Affecting Deaf People

Principal Investigator: Robert Pollard, PhD

**Purpose of the Project:** To conduct research to identify factors affecting intimate partner violence (IPV) in the Deaf Community, with the ultimate goal of informing the development of IPV prevention and intervention strategies targeting the deaf population, as well as guiding further research.



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## Research Updates from NCDHR

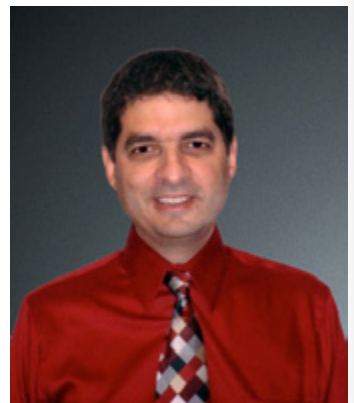
**What happened in 2012:** We began our third and final year of this research project on August 1, 2012. During this past year, we completed 15 videophone interviews with deaf persons (men and women) who have experienced intimate partner violence (i.e., IPV victims/survivors). We have just begun interviewing persons who have been violent (i.e., IPV perpetrators) in relationships where one or both persons was deaf. In our first project year, we interviewed 21 persons who provide IPV services to the Deaf persons. An article describing the service provider interview results has been accepted for publication in the *Journal of Interpersonal Violence* and an article regarding the victim/survivor interview is being written. In this past year, presentations regarding our findings from the victim/survivor interviews and the service provider interviews took place at the conference of the European Society on Mental Health and Deafness (Lisbon, Portugal), the Justice for Deaf Victims National Coalition (Denver), the American Society of Criminology (Chicago) and at a conference entitled "Intimate partner violence: Innovations in the field" (Rochester, NY).

### **Deaf Sign Language Users, Suicide, and Social Network Characteristics**

**Principal Investigator:** Steven Barnett, MD

**Purpose of the Project:** From the findings of the 2008 Deaf Health Survey, the Rochester Deaf community identified suicide risk as an important topic for further research and intervention. The goal of this research is to explore the relationship of social connectedness and suicide risk with deaf adult ASL users.

**Plans for 2013:** We plan to measure social connectedness with the Interpersonal Needs Questionnaire (INQ), a 15 question survey that NCDHR translated, filmed and tested. We plan to use new web-based survey software, that uses video, with the INQ and other questions (about suicide attempts, depression, and related topics) to survey 300 deaf adults over the internet.



### **2012 Publications**

For a copy of an article, please email [Erika\\_Sutter@urmc.rochester.edu](mailto:Erika_Sutter@urmc.rochester.edu)

- McKee M, Thew D, Starr M, Kushalnagar P, Reid JT, Graybill P, Velasquez J, Pearson T. Engaging the Deaf American sign language community: lessons from a community-based participatory research center. *Progress in Community Health Partnerships: Research, Education, and Action*. 2012 Fall; 6(3): 321-9.
- Smith SR, Chin NP. Social Determinants of Health in Deaf Communities (book chapter). In: J. Maddock, ed. *Public Health – Social and Behavioral Health*; 2012. Available at: <http://www.intechopen.com/books/public-health-social-and-behavioral-health/social-determinants-of-health-disparities-deaf-communities>
- Thew D, Smith S, Chang C, Starr M. The Deaf Strong Hospital Program: a model of diversity and inclusion training for first-year medical students. *Academic Medicine* 2012; 87(11); 1496-1500.

NCDHR articles to be published in 2013 ("in press"):

- Chin NP, Cuculick J, Starr M, Panko T, Widanka H, Dozier A. Deaf Mothers and Breastfeeding: Do Unique Features of Deaf Culture and Language Support Breastfeeding Success? *Human Lactation* (in press 2013).
- McKee M, Smith S, Barnett S, Pearson TA. What are the Benefits of Training Deaf and Hard-of-Hearing Doctors? *Academic Medicine* (in press 2013, invited commentary).
- McKee M, Thew D, Schlehofer D. Ethical Issues in Conducting Research with Deaf Populations. *American Journal of Public Health* (accepted for a special issue on research ethics, to be published in 2013).

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## Research Updates from NCDHR

- Pollard RQ, Sutter E, Cerulli C. Intimate partner violence reported by two samples of deaf adults via a computerized American Sign Language survey. *Journal of Interpersonal Violence* (in press 2013).

### *In case you missed it. . .*

NCDHR 2008 Deaf Health Survey results reported in American Journal of Public Health, with ASL video adaptation:

- Barnett S, Klein JD, Pollard RQ, Schlehofer D, Starr M, Sutter E, Yang H, Pearson TA, for the NCDHR. Community participatory research with deaf sign language users to identify health inequities. *American Journal of Public Health*. 2011;101(12): 2235-8.

Click here for ASL video adaptation of this article with English captions: <http://ajph.aphapublications.org/page/VideoArchive> (scroll down to 2nd video)

### **2012 Presentations**

In 2012, our faculty, staff, and partners gave 13 presentations about NCDHR-related research at national scientific conferences:

- 3 presentations at the National Institute of Health’s “Science of Eliminating Health Disparities” Summit
- 4 presentations at the American Public Health Association (APHA) annual meeting
- 1 presentation at the Agency for Healthcare Research and Quality (AHRQ) Annual Conference
- 1 presentation at the Society of Behavioral Medicine annual meeting
- 2 presentations at the American Heart Association’s Epidemiology and Prevention scientific sessions
- 1 presentation at the Early Hearing Detection and Intervention (EHDI) annual meeting
- 1 presentation at the first-ever Deaf Mental Health Research Priority Consensus-Planning Conference held at Gallaudet University

## **NCDHR HAPPENINGS**

## **AllOut Marketing Marketing Agency Hired to help move NCDHR Above and Beyond**

NCDHR has undergone a fast-paced transformation from a small research center with a single research project to a busier center with several research projects happening at the same time. Dr. Pearson once commented thoughtfully in this 2012 annual report to NCDHR stakeholders (December 2012 Healthy Signs Newsletter) that it is wise to “pause” and “reflect” from time to time by putting NCDHR under a microscope and to see where NCDHR can even do better! That is where the AllOut Marketing comes into the picture. NCDHR has contracted this agency, based in Minnesota with an office here in Rochester, to find out what the community thinks of NCDHR and how the center can improve its outreach and promotions. The agency’s Chief Creative Officer, Alicia Lane-Outlaw, happens to be a member of the Deaf Health Community Committee (DHCC), an advantageous plus for the center. AllOut has considerable marketing experiences with Deaf, hard of hearing and DeafBlind organizations. For more information about AllOut marketing, check out their [website](#).

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Sign Language for Deaf audiences. A series of those films for the Centers on Disease Control include students from RSD and scenes from the campus.

(article from [http://www.rsdeaf.org/pdfs/BF\\_Fall12Win13hires.pdf](http://www.rsdeaf.org/pdfs/BF_Fall12Win13hires.pdf); see page 2)

## Dr. Robert Pollard Receives the Lyon Founder's Award

### from the Rochester School for the Deaf

The Rochester School for the Deaf (RSD) recently honored Dr. Robert Pollard, JR. with the 2012 Lyon Founder's Award in recognition of his numerous initiatives pertaining to mental health, public health, sign language interpreting, and professional education opportunities for deaf people.



Bob is a Professor of Psychiatry at the University of Rochester School of Medicine and Director of the Deaf Wellness Center.

Under his leadership, Bob and the Deaf Wellness Center have received numerous awards for excellence in clinical service, research, and teaching.

Bob writes and lectures widely on a variety of mental health and healthcare topics affecting deaf consumers and professionals. He has been principal investigator on over 50 Federal, foundation, regional, and local grants, totaling over 5 million dollars, and he has published over 90 articles and book chapters, and produced 15 films in American

## Where are they now?

### Tara Holaday

In the summer of 2011, Tara Holaday was one of three interns that worked with NCDHR. Where is she now? Recently graduating from the Rochester Institute of Technology (RIT) with her degree as a Biomedical Sciences major, Tara is contemplating what her next steps should be. In her most recent year at RIT, Tara had the opportunity to take a class focused on Deaf education. This has triggered a passion in her that she previously did not realize.



She is currently working towards getting her Masters of Science in Secondary Education from the National Technical Institute for the Deaf (NTID). Once she has graduated, she is contemplating either moving on to get her PhD related to sensorineural hearing loss and hidden health conditions behind it, or continuing on to get her DPT in Physical Therapy or her Athletic Training Certificate (ATC). Regardless of her decisions to come, NCDHR wishes her the best and is proud of her achievements thus far.

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## Healthy Living with Hearing Loss

### New community committee for people with hearing loss

**Vision Statement:** To affect public policy supported by evidence-based research, to identify health risks associated with hearing loss and to promote their solutions.

**Mission Statement:** To study the relationship between hearing loss and health by partnering with the community of people with hearing loss, clinicians and researchers.

When NCDHR began working with the Deaf Community in 2004, they also had drafted in a time period when they would begin working with the community of people with hearing loss. Now is that time. With the assistance from NCDHR, a group recently formed called the Exploratory Task Force. This group consisted of people with hearing loss from the Rochester Community. After several meetings, this group drafted a mission and vision statement (see above) and came up with a new name for the Task Force: The HL2 (Healthy Living with Hearing Loss).



Mary Chizuk, Chair of HL2

The process that this group went through was similar to the process the Deaf Health Community Committee (DHCC) went through when NCDHR originally started working with the Deaf Community in Rochester, NY. The newly formed HL2 consists of people with hearing loss from the Rochester community, many of which are also part of the HLAA (Hearing Loss Association of America – Rochester Chapter) however, the group will include anyone from the Rochester greater community that has a hearing loss.



Don Bataille



Elise DePapp



David Koon

The current chair of the HL2 is **Mary Chizuk**. The group is currently working on forming a leadership team which consists of **Elise DePapp**, **Don Bataille**, and **David Koon**. Within the past few months, HL2 has begun joining NCDHR's Executive Committee meetings. They have also begun asking the local community for people with hearing loss, what their health priorities are. The HL2 has passed out questionnaires they created to other people with hearing loss in the community, and

will use this information to help NCDHR find the major health priorities in the Rochester community of people with hearing loss in order to promote a healthier community.

This group is working with NCDHR to study what other health problems may arise because of our hearing loss. If you know of anyone with a hearing loss that may be interested in joining HL2 please have them contact Jamie Marsden at [Jamie\\_Marsden@urmc.rochester.edu](mailto:Jamie_Marsden@urmc.rochester.edu) and she can put you in touch with our group.



**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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