

Healthy Signs

National Center for Deaf Health Research January 2014
Rochester Prevention Research Center

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**Happy New
Year!**

A Message from
the Director

Happy New Year!

A message from the Director
Steven Barnett, MD



Happy New Year! This year, 2014, is an important year for NCDHR. September 2014 will be the 10th anniversary of NCDHR, officially established in 2004 with the name “Rochester Prevention Research Center (RPRC): National Center for Deaf Health Research (NCDHR).” Together we have accomplished so much during these 10 years. In Summer 2013, during a NCDHR Community Forum co-hosted with DHCC (Deaf Health Community Committee), some Deaf people said that the Rochester Deaf community is healthier since NCDHR was established.

Over the past 10 years, together we have modeled a way that Deaf and hearing researchers and community members can work together successfully. We have raised awareness and changed attitudes regarding Deaf community strengths, health priorities, healthcare disparities, and the value of inclusion and collaboration. We have strengthened relationships with local and national partners, and developed new relationships, leading to new programs and opportunities. Our network of partners continues to grow.

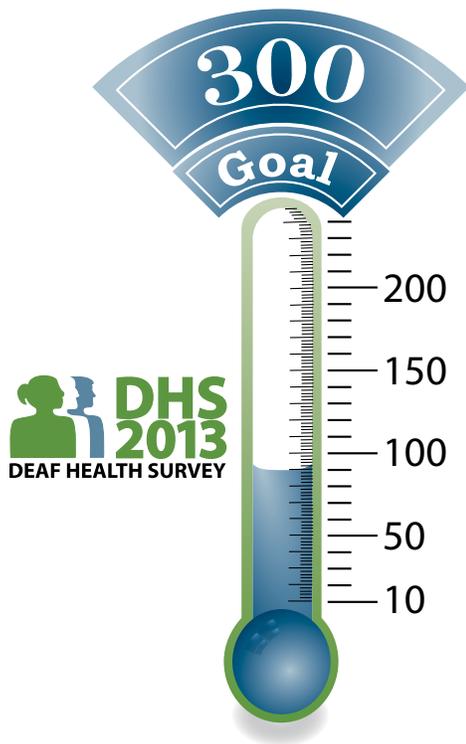
Some of our current grant-funded projects continue until 2018.

We have also worked together on education programs. We have trained deaf, hard-of-hearing and hearing students, fellows, and faculty about collaborative health research with Deaf sign language users. We have worked together to teach medical students, pharmacy students, and faculty about work with Deaf patients and their families and patients with hearing loss and their families. We have worked locally and nationally to advocate for including people who are deaf or have a hearing loss in all healthcare careers, including as doctors and nurses. I see that attitudes are changing.

. . . our work together with two very different populations - Deaf sign language users and people with acquired hearing loss - . . . helps us stand out.

We have joined together with new and existing public health programs, creating new opportunities to include Deaf people in health promotion programs. One example is the Deaf Farm Stand hosted by

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the Rochester Recreation Club of the Deaf (RRCD), but there are also other examples related to blood pressure and HIV. The Deaf Health Survey (DHS) is the only ongoing public health surveillance in sign language anywhere in the world. So far, this is only happening here in Rochester, but we hope that after we demonstrate our success, other communities will begin to use the Deaf Health Survey. Please help support this success by taking the DHS and encouraging your friends to take the DHS, too.

Please help support this success by taking the DHS and encouraging your friends to take the DHS, too.

To learn more about the DHS 2013, [see page 9](#), or [watch this video](#).

We still have important work to do. Annual funding for NCDHR research and education programs has grown by more than 300% since 2004, and some of our current grant-funded projects continue until 2018. We have other grant proposals that are being reviewed by the Center for Disease Control and Prevention (CDC) and the National Institute for Health (NIH). One of these proposals is to expand Deaf Weight Wise to reach more Deaf people. Another of these proposals is to add another research education program in collaboration with NTID that will increase the number of researchers who are Deaf or have a hearing loss. We have plans to submit more grant proposals this year, and the topics of these grant proposals are based on recommendations from our partner communities.

We are unique in our work together with two very different populations – Deaf sign language users and people with acquired hearing loss. This, along with our successes, helps us to stand out. More and more people know who we are and what we do together. The recognition comes from diverse sectors: public health, government agencies, Deaf communities, researchers, educators, students, and funders. I am enthusiastic about our successes, our momentum, and our direction. I look forward to continuing to work together with you this year. Happy New Year. This year, 2014, is an important year for us.

Steven Barnett, MD

Principal Investigator/Program Director
Rochester Prevention Research Center
National Center for Deaf Health Research

**NCDHR
HAPPENINGS****Who works at NCDHR?
Meet the Staff**

Hello! Welcome to NCDHR, how may we help you?

Interested to learn more about the staff at NCDHR?



Steven Barnett, MD
Principal Investigator /
Program Director

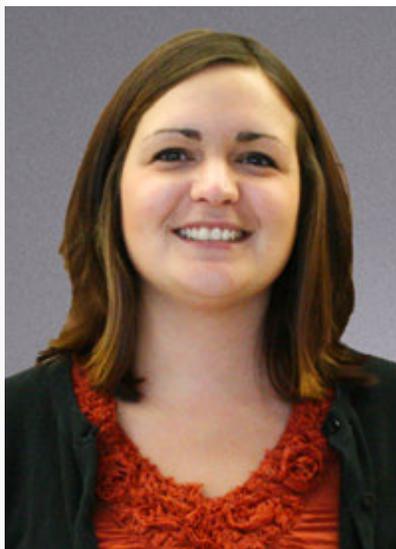
Steve Barnett, MD, is the current director of NCDHR. Prior to his work with NCDHR, he was a practicing family medicine physician. Steve has worked with the Deaf community and the community of people with hearing loss for a long time. He was one of the original founders of NCDHR, working with the Rochester Deaf Health Task Force that set up NCDHR in 2004. As a family medicine doctor, Steve worked at the Folsom Medical Center. His work with Deaf patients and their families inspired his curiosity and he decided he wanted to know more about the Deaf community and the community of people with hearing loss. This led to his primary focus switching from his work as a doctor to his current focus: research. He became a key researcher at NCDHR focusing on the Deaf community and their health and healthcare. In the past several years, this research focus has grown to include the community of people with hearing loss.



Erika Sutter, MPH
Senior Health Project
Coordinator

Erika Sutter, MPH is the Senior Health Project Coordinator for NCDHR. She has been working with NCDHR since 2004 - so she has seen how much NCDHR has grown and accomplished by working together with our local Deaf community. She helps to plan, organize, and carry out research projects with the research team. She also supervises NCDHR staff, helps to write new grant proposals, and helps recruit research participants. She has been learning ASL for almost 4 years.

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Kelly Matthews, BSW
Health Project Coordinator

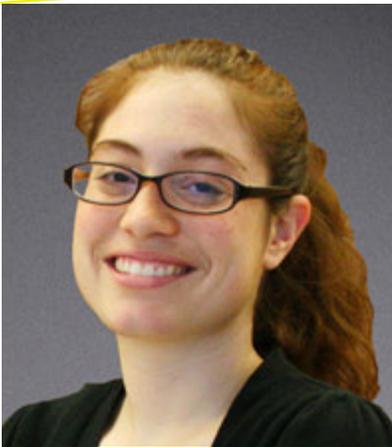
Kelly Matthews, BSW is a Health Project Coordinator. Kelly started work at NCDHR in October, 2012. She is originally from the small town of Stratton, Maine. She moved to Rochester for the first time in 2002 to obtain her Bachelors of Science degree in Social Work from the Rochester Institute of Technology. After graduation, Kelly lived in Massachusetts where she worked for DEAF Inc. as a Health Specialist, providing community outreach, HIV and health education in the Greater Boston area. Afterwards, she moved back to Maine where she worked for the Community Counseling Center in rural Maine as a Case Manager assisting deaf adults, children and their families. Kelly moved back to Rochester in 2009 and was employed by the Rochester School for the Deaf's PRIDE Program before joining NCDHR. Kelly is a counselor for Deaf Weight Wise, and also works with the Deaf community as part of the Community Transformation Grant (CTG) known as H.E.A.R.T., (Health Engagement and Action Towards Rochester's Transformation). You may have seen H.E.A.R.T and Kelly's efforts in action this past summer at the Deaf Farm Stand at RRCD. To learn more about the H.E.A.R.T. Initiatives, please see www.RocHEART.urmc.edu.



Lori DeWindt, MA
Health Project Coordinator

Lori DeWindt, MA. is a Health Project Coordinator. Lori graduated from Gallaudet University in Washington DC with a Masters degree in Mental Health counseling and an undergraduate degree in Social Work. Lori has worked at NCDHR since 2011. Her major focus with NCDHR is the Deaf Weight Wise project and the DWW VP pilot. Lori also works at the Deaf Wellness Center (DWC) in the Department of Psychiatry at the University of Rochester as a Psychotherapist. She plans and coordinates research projects for both the DWC and NCDHR.

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Jackie Pransky, BS
Research Assistant

Jackie Pransky, BS is a Research Assistant. Jackie was born and raised in Massachusetts. She moved to New York in 2008 to attend the Rochester Institute of Technology (RIT). In 2011 she worked at the Deaf Studies Lab at RIT for her co-op experience. She graduated from RIT in 2012 with a Bachelors of Science in Clinical Psychology. Since then, she became a research assistant for NCDHR. She worked with Dr. McKee on his project on the effect of health literacy on Cardiovascular risk factors in deaf and hearing populations in Rochester. She also assists Dr. Scott Smith on his project on Adolescent Cardiovascular Health Literacy and NCDHR's major projects; Deaf Weight Wise and the Deaf Health Survey 2013. As a research assistant, Jackie interviews participants, recruits, does data entry, and supports the different research projects at NCDHR.



Kim Kelstone, CI/CT, RN
Communication Access Coordinator /
Sign Language Interpreter

Kim Kelstone, CI/CT, RN is the Communication Access Coordinator / Sign Language Interpreter. She has been working directly with NCDHR since 2009, though has been aware of and involved with NCDHR before that. Kim's primary responsibility is to ensure that meetings, presentations and events NCDHR staff and partners are attending are fully accessible to all through ASL/English interpretation, captioning and audio support. She is also a member of NCDHR's [Translation Working Group \(TWG\)](#). Kim currently works part-time, and she recently completed nursing school and became a Registered Nurse (RN).



**Jamie Marsden, BFA,
MSSEd, SPT**
Secretary

Jamie Marsden, BFA, MSSEd, SPT is a Secretary. Jamie currently works part-time with NCDHR as she attends Nazareth college full-time, working towards her Doctorate in Physical Therapy. Jamie has worked at NCDHR since September of 2010. Prior to NCDHR, she substitute taught at the Rochester school for the Deaf for a few years. She is originally from Roselle, NJ, but moved to Rochester in 2002 to attend the Rochester Institute of Technology (RIT). She received her Bachelors in Fine Art from RIT in 2006 and her Masters in Deaf Education from NTID in 2008. Jamie's main responsibilities are graphic design, website design and update and secretarial work. When needed, Jamie also does video filming and editing, photography, data entry, and data collection, and other tasks to support NCDHR activities

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New NCDHR Website Stay tuned for more updates!

As the new year begins, NCDHR continues to grow and evolve. NCDHR is proud to announce the launch of their new website! To navigate the new website, [click here](#).

NCDHR is also currently working on improving the new website. One improvement to come is on the Leadership and Staff page. Staff pictures, that are currently on the page, will be replaced with short videos of the staff member signing for themselves. This is in an effort to make the NCDHR page more ASL friendly for our Deaf community friends. For those of you who don't know ASL, everything will either be captioned, or the word-for-word English translation will be shown under the video. Please check the website soon for this update!

Keep checking NCDHR's new website for more videos in ASL!

Leadership & Staff

Director

Steven Banez, MD
Principal Investigator/Program Director
Rochester Prevention Research Center
National Center for Deaf Health Research
Associate Professor, Department of Family Medicine and the
Department of Public Health Sciences
University of Rochester Medical Center
steven_banez@urmc.rochester.edu

Staff

Video 1: Hello, I'm Erika Suffer. I'm the lead research coordinator here. I've worked here since 2004. I help our team design new projects, collect research data, and analyze data. I also help write proposals for new grants. I supervise other people here too.

Video 2: Hello, My name is Jackie Pransky. I work at NCDHR as a Research Assistant. I graduated from RPI with a major in Clinical Psychology in 2012. My job at NCDHR changes every day. I do data entry, I work with people and I help set up things for different research projects. I really enjoy working with the Deaf community and NCDHR.

Research Opportunities

Deaf Health Survey 2013

300 Goals

To learn more about the Deaf Health Survey 2013, [click here](#).

To sign up for this survey, email [Kelly Matthews](mailto:Kelly.Matthews@urmc.rochester.edu).

NCDHR What's New?

An update on staff
and current projects from the
Rochester Prevention Research Center,
NCDHR.

*Interested in watching an ASL video
about the staff and the current
projects at NCDHR?
[Check out this video!](#)*

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NCDHR Hosts a Medical Student Carolyn Stwertka joins NCDHR for January

Carolyn Stwertka is a fourth year medical student at SUNY Upstate School of Medicine in Syracuse, NY. For the month of January she is doing an elective in Deaf Health with NCDHR. Her studies of American Sign Language and Deaf Culture began at Webster Schroeder High School and continued at the University of Rochester where she majored in Psychology. Her goals for this month are to learn more about Deaf Health, increase her American Sign Language skills, and learn about the research going on at NCDHR. She plans to pursue a career in Pediatrics and ultimately settle in the Rochester area.



Farm Stand Finale

Harvest Festival Ends the Farm Stand for 2013

On behalf of Foodlink, NCDHR, and the Rochester Recreation Club for the Deaf (RRCD), we would like to say THANK YOU to all who supported our Farm Stand this past summer at RRCD. This stand was set up as part of both Rochester's Community Transformation Grant - H.E.A.R.T. (Health Engagement and Action for Rochester's Transformation) and the Department of Agriculture's Fresh Connect Grant. The purpose of this stand was to provide underserved communities in the greater Rochester area, with access to fresh, local produce at affordable prices. For the grande finale, NCDHR hosted one more Farm Stand on October 19th, 2013. It was an excellent year and thank you again for your support!

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To see more photos from this year's Farm Stand, [click here.](#)



Deaf Health Survey 2013

FAQs



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What is the Deaf Health Survey 2013?

The Deaf Health Survey is NCDHR's **new** survey. We did the Deaf Health Survey 2008 and would like to compare that information to the data we find this year. The DHS 2013 has general health questions and also specific health-related questions that mirror the Telephone Surveys done by the Centers for Disease Control (CDC). This survey is separate from surveys used for Deaf Weight Wise or other ongoing projects. We started collecting this survey data

in September 2013, and will continue until 300 participants have taken this survey. We have almost 100 so far!

To see how far until we reach our goal, [click here](#).

Why should I take the Deaf Health Survey?



The CDC and Monroe County Department of Health have done surveys with the general population through the phone. Deaf people are not included in this data! We need deaf people to participate in this survey to assist NCDHR with proposing new projects. The Deaf Health Survey 2008 is why we have our current projects such as Deaf Weight Wise (DWW). In order for us to know what research to do next, we need data to prove it's needed by the community. The Deaf Health Survey will allow that.

How long does it take?

So far, we have had a range of time from 20 minutes to an hour. This is because the Deaf Health Survey is conducted in American Sign Language (ASL) video with English support. Some participants may decide to watch the signing videos; some may decide to focus on the written questions. Again, it will be your choice as to which one you'd like to use.

Where can I take the survey?

You can take the survey almost anywhere. NCDHR will be at several community events, either taking appointment times or hosting the survey. You are more than welcome to come to the NCDHR suite at the [Saunders Research Building](#) and we will provide a parking pass or free bus tickets. We can also arrange to meet in a public place, or even arrange a home visit if you are unable to travel. Better yet, invite us to give a presentation and host the survey at your club or organization's next meeting!

How do I sign up?

Contact Kelly Matthews at Kelly_Matthews@urmc.rochester.edu or by VP (585) 512-8519



To learn more about the Deaf Health Survey 2013, [click on the video above](#).

DHCC News Briefs from 2013

An update and plans to come

Written by DHCC Past Chair, Val Nelson-Metlay

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Farm Stand

Over the summer, some DHCC members were among the volunteers at the Foodlink Farm Stand. The Farm Stand was held on Saturdays at the Rochester Recreation Club for the Deaf.



DHCC Retreat

DHCC held its retreat on July 27, 2013 at the Gates Public Library. We wish to thank the library for its meeting room and for its help with technical set-ups. The retreat was to update the DHCC Governance Guidelines. Unfortunately, we ran out of time to discuss our name change (DHCC does not fingerspell easily) and to learn from LaToya Sanchez, a current member of DHCC, how to use social media to help benefit DHCC.



Community Forums

Beth Metlay, current Chair of DHCC, and Val Nelson-Metlay, Past Chair of DHCC met with NCDHR to organize the Community Forums. This was in an effort to find out what the Deaf community's wishes are on health research. The Deaf and Hearing Loss communities' feedback helped NCDHR to see what research needs to be done. One example would be how underemployment affects the health of the Deaf and Hearing Loss communities.

Four Community Forums were held, two hosted by the DHCC and two hosted by the HL2. On the last forum hosted by the DHCC, the DHCC surprised Dr. Thomas Pearson with a stained glass picture of grapes to honor his work with the community. The grapes represented his passion of making wine at his winery. The stained glass was created by Jackie Scherz as a gift to Dr. Pearson.



Deaf Health Fair

Plans are starting up for next summer's 2014 Deaf Health Fair. The Fair will alternate every other year with the Deaf Festival to avoid the overwhelming affect of too many events for the Rochester Deaf community.

DHCC Updates

DHCC welcomes 4 new members: Catherine Stutzman, Kathy Dollinger-Meyer, Jason Rotoli and Diane Plassey Gutierrez. DHCC is continually looking for new Deaf community members. In October, Beth Metlay became the new Chair and Val Nelson-Metlay became the Past Chair.

Two people left NCDHR/DHCC: Dr. Mike Mckee and Matt Starr. We wish them all the luck in the world. If you see them, give them a high-five.

HL2 News Briefs from 2013

Written by Elise DePapp

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HLAA - Rochester chapter Celebrates its 30th Anniversary

Some members of NCDHR's Healthy Living with Hearing Loss (HL2) Community Committee are also members of the Hearing Loss Association of America - Rochester Chapter. This fall, the HLAA-Rochester Chapter celebrated its 30th year as an organization supporting people with hearing loss through education, information, and advocacy programs. The HLAA - Rochester Chapter hosted a Gala Event on November 3rd, 2013 at the Grand Ballroom, The Inn on Broadway, in Rochester, NY.



Many were reunited with friends and enjoyed a special program featuring a dance performance by the RIT/NTID Dancers under the direction of Thomas Warfield. Hors d'oeuvres, a multi-level dessert display and non-alcoholic punches and a cash bar were provided throughout the evening. The event was ADA accessible and the Gala had a hearing loop, captioning and interpreting services.

National HLAA Convention, Portland Oregon

Three members of the Rochester chapter of HLAA attended the National Convention in Portland, Oregon, June 25-30, 2013. Technology and Communications were the most numerous topics presented, both in the Exhibit Hall (half of the 61 exhibitors), and in the Workshops. Williams Sound, Harris Comm., HARC Mercantile are some of the many businesses providing hearing assistive and safety alerting devices: FM, IR, Bluetooth systems, pocket talkers, amplified phones, loud alarm clocks, door bell and smoke alarm alerts, and more.

The 38 Workshops were grouped into: Advocacy, Assistive and other technology. More advocacy and technology, hearing aids and CI's, relationships and communication. The sessions lasted 45 to 75 minutes and were done by individuals or panels of presenters. Questions were usually held until the end. All conference rooms had ALDs, either loops or infrared, in addition to captions and interpreters. Included in advocacy were updates on the ADA regulations; emergency preparedness for those with hearing loss (such as the recent Monroe County announcement of "texting to 9-1-1" service...on Verizon phones now; Monroe County is the second in NYS to provide this service); and hospital situations. Smart phone and wireless industry workshops were very well attended, and highly technical. Finding the Cell Phones or Mobile Devices to Meet Your Need; and, Facilitating Communication with Smart Phone Technologies, are two examples of technology/communications workshops.

Two of HLAA's previous Featured Speaker Program guests, Sam Trychin and Gael Hannon, did workshops on relationships and communication. One of HLAA's PAC members, Allen Ford, was the moderator at a special session for Veterans with hearing loss. For the complete schedule see the Convention website, www.eventmobi.com/HLAA2013. Several of the workshop notes include slideshows; others have a brief description of the subject. Take a look at this site—it will give you a good idea of what the Convention had to offer. We also had some great social events. Next year's Convention is in Austin, Texas; a little closer to home. You'll meet HLAA's new Executive Director, Anna Gilmore Hall, at the September 10th chapter meetings.

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HL2 News Briefs from 2013

Written by Elise DePapp

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Dr. John W. Cornforth

Imagine a **Nobel Laureate** who traced their achievements to hearing loss! John W. Cornforth, an Australian born scientist (b. 1917), was encouraged to pursue chemistry as a career because a high school teacher recommended that field of work. Dr. Cornforth began to lose his hearing at age 10, due to otosclerosis; he entered university at 16 and by the time he graduate 4 years later, he was profoundly deaf, unable to hear any lectures. He won the Nobel Prize in chemistry in 1975, for research in the biosynthesis of cholesterol. Dr. Cornforth himself said little about his deafness, other than to say “my wife has eased for me beyond measure the difficulties of communication that accompany deafness”. He used lip reading, and compensated for his inability to hear during lectures by visiting chemists by gleaning the content of their speeches from the slides they showed, and he asked the most perceptive questions at the end of the talks. A former colleague said that other

deaf people wrote Dr. Cornforth asking for advice, and that he had been a great inspiration to young deaf people. (NYT obit 12/20/2013). Nothing is mentioned as to whether or not Dr. Cornforth ever used hearing aids, Cochlear Implants, or sign language.

To read more articles written by Elise DePapp from the HLAA newsletter, [click here](#).



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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