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Looking back at the beginning of this year, there have been so many success stories from NCDHR and these stories continue to exceed expectations. What made this even more impressive is that our center continues to grow in the face of diminishing resources. Yet, this comes as no surprise because of the talented and dedicated faculty, staff and community partners brought together with perseverance to transform our center from its infancy to a noteworthy academic-community research organization. I wanted to share some of our success stories…

• Moving research into action! By working together, our community partners and NCDHR have identified strengths and disparities affecting the health of the Deaf community. We compared the findings between the Deaf Health Survey 2008 (DHS 2008) and the 2006 Monroe County Adult Health Survey (made up of people who responded to the survey by voice telephone). One of the strengths from the Deaf community was its low smoking rate. However, the data from DHS 2008 revealed that the Deaf community experienced higher rates of obesity, suicide ideations (thinking about suicide), and Intimate Personal Violence (IPV) when compared with the hearing people. We took action to address these health disparity findings:

1. NCDHR is now halfway through completing its historic first randomized clinical trial with 104 Deaf research volunteers enrolled in the Deaf Weight Wise Research Study to determine the effectiveness of a healthy lifestyle intervention.
2. NCDHR has successfully secured a grant from the National Institutes of Health to study suicide and social networking within the Deaf community.
3. NCDHR collaborated with Deaf Wellness Center to secure a grant from the Centers for Disease Control and Prevention to better understand the factors related to victimization and perpetration in Deaf relationships.

• Broadening our horizons! NCDHR has received another grant that would protect Deaf people interested in participating in a research study. By working with Deaf Wellness Center, Clinical and Translational Science Institute and the Deaf community, we are seeking effective ways to make informed consent more easily understood by Deaf American Sign Language users. The goal is to ensure that a Deaf ASL user can independently make his or her decision on whether or not to participate in a research study. The study will also have important implications on obtaining consent for medical procedures. Being an informed person also helps greatly in breaking down mistrust with researchers and/or healthcare practitioners. (For more information about this Informed Consent grant, click this link).

• Better diversity among health care professionals! While the main goal of NCDHR is to deliver generalizable knowledge and research data to eliminate health disparities within deaf and hard of hearing populations through community-based participatory research, at the same time, we are actively pursuing other equally important goals. One of them is to provide training and opportunities for qualified deaf and hearing students,
ranging from high school to post-doctoral programs, to pursue careers in Deaf health research. By taking the initiatives recommended by the Task Force on Health Care Careers for the Deaf and Hard-of-Hearing Community, NCDHR has submitted two major grants: One grant proposes up to nine deaf postdoctoral fellowship positions to develop scientific careers in Deaf Health research and teaching. The second grant intends to provide barrier-free avenues for deaf people who already have earned their masters in biomedical sciences to pursue doctoral studies at a research-intensive institution right here at the University of Rochester. Additionally, summer programs and internships in Deaf Health research and medicine are open to interested deaf high school and undergraduate students. Please check our NCDHR website for more information about these summer opportunities.

• New Community Partner! NCDHR has welcomed a new community partner this year. Local members of the Hearing Loss Association of America – Rochester Chapter have formed a task force to examine health issues among people with hearing loss. They have renamed their task force to, “Healthy Living with Hearing Loss.” The Task Force’s objective is to solicit information from individuals with hearing loss and their families to identify and prioritize their distinctive community health research questions. Mary Chizuk, RN, a member of the HLAA-Rochester Chapter and a nurse with the local Veterans Administration, is currently the chair.

• Pursuing our 3rd 5-year funding application! Lastly, but not least, in this summer of 2013, NCDHR will be applying for its third round of funding support from the Centers for Disease Control and Prevention. As a community-based participatory research center, our partners and NCDHR will be hosting several Town Hall meetings with the Deaf community as well as community members with hearing loss. The purpose of these meetings are to update all of our stakeholders on what has been happening with health disparities research and to discuss what new research questions we should be focusing for the next 5-year cycle (2014-2019). We will communicate with all of our stakeholders and invite each of every of you to join these important discussions that would greatly help the direction of our community-based participatory research endeavors.

There are so many more success stories to share with all of you. We will continue to find ways to share these stories through our website, this newsletter and open houses and town hall meetings now being planned.

Without doubt, we will have more challenging years ahead of us. However, I have every confidence that with all of our talented and dedicated researchers and community partners, we can look forward to yet another year of exceptional growth with new milestones that bring all of us closer to our ultimately long term goal – that is – to promote a healthier community for Deaf people and people with hearing loss. Have happy and healthy holidays to all of you.

Dr. Thomas A. Pearson
Principle Investigator/Program Director
National Center for Deaf Health Research
Documents that explain life-saving medical procedures or how to take part in research can be difficult to understand, but with a $600,000 grant the University of Rochester Medical Center is studying new ways to deliver those messages to deaf patients and consumers.

Robert Pollard Jr., Ph.D., and colleagues have begun a project to evaluate informed-consent procedures for people who primarily use American Sign Language (ASL). Researchers will compare the effectiveness of three informed-consent options: typical English-language forms, a filmed ASL interpretation of the informed-consent documents, and a filmed, scripted scenario in which several deaf people have a conversation about the information contained in the source documents.

Using video as a tool to communicate information to members of the Deaf community is already underway at the National Center for Deaf Health Research (NCDHR) at URMC. However, putting the three options to a scientific test will allow researchers to know what works best. Many deaf people have low English-language reading ability, and therefore are often excluded from medical research and health surveillance.

“We have a lot of experience with people who don’t understand forms,” said Pollard, professor of Psychiatry and director of the URMC Deaf Wellness Center. He also works closely with the NCDHR and has produced numerous ASL films for deaf audiences about health. “Since English literacy is a struggle for many people, we hope that the video-based communication methods we’re studying will have implications for not only the Deaf community but for other language minority groups, and even young children.”

“Deaf ASL users are often excluded from research on health, and it is rare to have research consent information presented in ASL,” added Patrick Graybill, past chair of the Deaf Health Community Committee, a community partner of NCDHR, who also has been involved in many ASL films. “Determining best practices for informed consent with Deaf ASL users is an important step for inclusion and to improve the protection of Deaf research participants.”
Another objective is to measure which communication method best engenders trust and a willingness to engage in clinical research. Principal investigator is Thomas A. Pearson, M.D., M.P.H., Ph.D., the Albert D. Kaiser Professor who directs both the NCDHR and the Clinical and Translational Science Institute (CTSI). Steven Barnett, M.D., associate director of the NCDHR is a co-investigator, along with several members of the University’s Institutional Review Board, which is responsible for protecting research volunteers and educating doctors and scientists.

“We are very grateful for the research grant, and we all agree on the importance of assuring that deaf and hard-of-hearing persons understand what it being asked of them when they enroll in a research study, and to encourage participation in research,” Pearson said. “Our study also has implications for informed consent for clinical care, such as surgeries and vaccinations, and will be done in partnership with the Rochester Deaf community, to provide better patient-centered care in the future.”

Funding for the four-year project was provided to the University of Rochester CTSI (award number 8-UL1-TR000042-07S2), through the National Center for Advancing Translational Sciences and the National Institute for Deafness and Other Communication Disorders, both of the National Institutes of Health.

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**Grant Received for the Research Study on Informed Consent**

www.urmc.rochester.edu/news/story/index.cfm?id=3656

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**Are you Interested in Helping us with a Survey?**

Deaf Health Literacy and Cardiovascular Risk Factors Study

We want to know if both deaf and hearing people experience healthcare in Rochester in a different way that might affect their heart health.

Dr. Mike McKee’s Health Literacy and Cardiovascular Risk Factors study will compare nearly 250 deaf and 250 hearing people to explore the relationship between their ability to understand health information and their risk for poor cardiovascular health. Dr. McKee hopes that this study will shed light on how the challenges in understanding the healthcare system can affect Deaf people’s cardiovascular health.

This study is currently accepting 40 to 70 years old deaf people. They will be paid for their time and a free parking ticket or bus pass will be provided as well. The survey will last one to two hours and can be taken at the Saunders Research Building. There will be different questions, on computer and on paper, about personal experiences with healthcare and knowledge of health factors. The height, waist, and weight of participants will be measured along with blood pressure. Blood samples will also be tested for cholesterol levels and diabetes.

If interested, please contact Jacqueline Pransky (Jacqueline_Pransky@urmc.rochester.edu) for more information or call her on VP: 585-568-6534.
Updates from the Deaf Health Community Committee (DHCC)

Patrick Graybill, now Past Chair of DHCC, a community partner of NCDHR since 2005, has passed the baton to Val Nelson-Metlay, as the DHCC’s newest chair. Her leadership team now consists of Beth Metlay, Vice-Chair, Arlene Sankey, Assistant Vice-Chair and Pat Graybill. DHCC also welcomed a new member, La Toya Sanchez, who underwent an orientation with Matthew Starr, Community Liaison between NCDHR and DHCC. La Toya is now studying to earn a degree in Information Technology, with a concentration in Web Game Developing and Stimulation. DHCC looks forward to having La Toya bring new ideas on how to improve its outreach and health education to the Deaf community.

NCC Meeting 2013
Trip to Maryland to Support Community-Based Participatory Research

Forty-six community partners representing 31 Prevention Research Centers (PRCs) throughout the country attended the National Community Committee’s (NCC) Annual Meeting last October 15 – 18 in Maryland. Four people represented our PRC, the National Center for Deaf Health Research (NCDHR): Patrick Graybill of the Deaf Health Community Committee, Matthew Starr, a community liaison faculty from NCDHR, Mary Chizuk and Don Bataille of the newly formed community organization called, “Healthy Living with Hearing Loss.” The purpose of the NCC Annual Meeting was to have a designated time and place to meet and share their experiences and lessons learned in a continued effort to enhance community participation in the PRC Program and other prevention research activities. NCC consists of leaders and members from communities that work closely with PRCs to do chronic disease prevention research through community-based participatory research. The NCC Annual Meeting was hosted by the University of Maryland PRC (Rochester PRC/NCDHR hosted the 2011 Annual Meeting).
Foodlink at the Deaf Club
A summary of a successful program

The Rochester Deaf community and Foodlink, a regional food bank, has concluded its first ever-successful collaboration to bring locally-grown food to the Deaf community. The goals of this collaboration were to bring fresh food at reasonable prices to an underserved community and to increase awareness about nutritional wellness. Some of our farm stand consumers were able to purchase healthy food through their SNAP (Supplemental Nutrition Assistance Program, also known as “food stamps”).

The Deaf Farm Stand ran from July through October at the Rochester Recreation Club for the Deaf (RRCD). Many thanks to RRCD and its board for their full support to have this farm stand on their property. Of course, without the volunteers to run this stand throughout the summer and fall, the Deaf Farm Stand would not have been feasible. Thanks go to the following volunteers: Susan Cherry, Robin Ching, Tom Coughlan, Dean DeRusso, Andy Foster, Davina Johnson, Beth Metlay, Val Nelson-Metlay, Jackie Pransky, Jim Pecora, Peg Prosser and Marie Tice. The Deaf Farm Stand plans to do this again during summer 2013. If you are interested in becoming a volunteer for this farm stand, please contact Kelly Matthews at NCDHR, kelly_matthews@urmc.rochester.edu.
Sprinkler System Break at the SRB
NCDHR and others are forced to temporarily relocate

On October 2, 2012, those working in the basement and parts of the first floor of the Saunders Research Building received quite a surprise. When trying to enter the Clinical Research Center (CRC) the door would not open. Facilities called for the assistance of Pat Pincus, the nurse manager from the CRC. As he opened the door, SWOOSH! They were soaked as a wave of water came rushing from the doors and raced down the hall and stairs.

While at his desk, in the basement, an employee of Academic IT was suddenly soaked to the bone as water came pouring from the ceiling as though someone had cut open a pool above his head. The water continued rushing from the ceiling and raced from the suite and down the basement hallway.

Erika Sutter was working in her office as water came gushing down the walls and started flooding the new NCDHR suite. She scrambled as fast as she could to rescue the electronic equipment that was on the floor of the suite. “Everyone’s being evacuated!” exclaimed a woman who had popped her head in the NCDHR suite. Erika quickly evacuated with the remainder of the employees. The employees waited patiently outside to learn more about what was happening.

Everyone was left bewildered and wondering what on earth had happened. Parts of the first floor were flooded and the entire basement had inches of water covering the floors. Sections of the CRC were filled with waist high water. After much confusion, it was discovered that the main line for the sprinkler system had been accidentally cut into during construction, causing the flood. What was to happen to all of these people that now needed a place to work?

Many of the departments which resided in the basement, were relocated to additional areas throughout the Saunders Research Building. Thanks to the Clinical and Translational Science Institute (CTSI), NCDHR was able to find a temporary home. Some employees of NCDHR worked at their alternate locations (Deaf Wellness Center, Family Medicine, and NTID). The rest of the employees were given extra offices and carrels spread amongst the employees of the CTSI. Graciously, the CTSI allowed NCDHR to remain in this suite until it was once again safe to return to the basement.

After about 6 weeks, the NCDHR has again moved back to their home in the basement of the Saunders Research Building. Facilities have done an excellent job working diligently to remove soaked portions of the walls, allowed them to dry, patched them up, and refinished the basement.

NCDHR sends their greatest gratitude to the staff of the CTSI for allowing them to use their office space and meeting rooms for the 6 weeks that NCDHR was displaced due to the flood. NCDHR also thanks the facilities for doing such a wonderful job fixing the basement after the catastrophic event. Thank you to all of the community members and others whom work with NCDHR that have been so patient while our meetings have been relocated due to the flood. With all of the confusion over, and the people and floors once again dry, NCDHR looks forward to returning to their home and continuing to work towards their mission.
New Staff at NCDHR

Kelly Matthews and Jackie Pransky

Jacqueline “Jackie” Pransky is excited to join the National Center of Deaf Health Research team. After completing required hours for her second co-op, she will soon have a Bachelor’s in Science degree (BS) in clinical psychology from the Rochester Institute of Technology.

Her job as a research assistant is to support the research team in their different research endeavors, such as Deaf Weight Wise. She also is currently running Dr. McKee’s Health Literacy on Cardiovascular Risk Factors study. Her favorite part of working at NCDHR is meeting people from all walks of life! She hopes that she can work with the Rochester community more in future.

Her first job in college was working as a resident advisor for three years. This experience assisted in her decision to pick psychology as her major. Her first co-op was working as an undergraduate research assistant at the Deaf Studies Lab in the National Technical Institute for the Deaf (NTID) under Dr. Hauser. A newly transferred New York resident, but still a Red Sox fan at heart, Jackie enjoys devouring books and biking in her spare time. Graduate school hangs in her future, but for now she is gaining experience through work because the “psychology field is very diverse so I need to narrow it down first.”

Kelly Matthews joined NCDHR in October as a full-time Health Project Coordinator. Kelly is originally from Stratton, Maine and has settled back in Rochester for the second time. She received her Bachelors of Science in Social Work from the Rochester Institute of Technology. For a brief time, Kelly lived in Massachusetts where she worked for DEAF Inc., in Allston, near Boston, as a Health Specialist providing outreach and health education to the deaf community. 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. Prior to joining NCDHR, Kelly moved back to Rochester, NY and was employed by the Rochester School for the Deaf’s PRIDE Program. Eager to return to the health and health research fields within the deaf community, Kelly’s primary focus will be on the Rochester Community Transformation Grant (CTG)/Health Engagement and Action for Rochester’s Transformation (H.E.A.R.T) and Deaf Weight Wise.
Mission of NCDHR: To promote health and prevent disease in the Deaf and hard of hearing populations through community-based participatory research.