

Healthy Signs

National Center for Deaf Health Research June 2013

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by Carlene Mowl

What is a pilot study?

You may have heard already that NCDHR is planning a pilot study of Deaf Weight Wise (DWW) that will be done over videophone (VP) instead of in person. NCDHR will be looking for about 8 people to participate in this project.

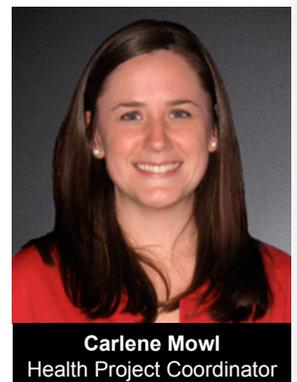
Pilot studies are small projects that are done to test an idea before doing a larger research study. NCDHR would like to know if the DWW 16 week program can be done over VP. The information the counselors will teach participants is the same, but interacting with a counselor over VP is different than going to group meetings. Because of the difference, it is a good idea to test the research idea with a few people first before doing a larger project.

What kinds of things can we learn from a pilot study?

- Are there any problems or barriers with the new method?
- Does the data show any trends? For example, did participants in the pilot study lose weight?
- Is a larger research project realistic? Larger research projects require a lot of time, money, and other resources. By testing our research project with a few people first, we can see if the resources we budgeted are enough.

What is the next step after a pilot study?

If the DWW VP pilot is a success then NCDHR can consider a larger research project in the future.



Carlene Mowl
Health Project Coordinator

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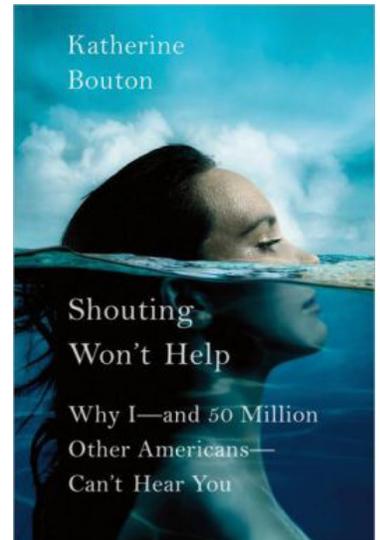
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Shouting Won't Help

A book review by Janet McKenna, MLS

Katherine Bouton, author of *Shouting Won't Help: Why I—and 50 Million Other Americans—Can't Hear You* (New York, Sarah Crichton Books, Farrar, Straus and Giroux, 2013) was amazed that “48 million Americans have some degree of hearing loss, 17 per cent of the population.” Like Ms. Bouton, a New York-based HLAA member, they deny the fact of their declining hearing. This book exposes readers to one person's trials of adult-onset hearing loss.



Ms. Bouton's well-written and extensively researched memoir traces

her sudden one-sided hearing loss as a thirty year old writer for the New Yorker through its slow bilateral decline until her present profound deafness at 65. Her inability to understand in noisy environments, on the telephone, and in the busy world led to forced retirement from her New York Times editorship.

Why Did My Hearing Vanish?

Ms. Bouton's bumpy road to a cochlear implant would be revealing to people with newly diagnosed hearing loss. Friends, family, and associates of such folks could understand better the reactions and relationships accompanying this disability after reading the book.

Ms. Bouton repeats her great difficulty coming to terms with her deafness. She admits pestering her doctors and audiologists for a cause (“idiopathic”) Ignoring it for the first twenty years, “existing in a relatively stable state of denial,” she writes, “when it could no longer be ignored, I spiraled into depression.” Even after receiving a cochlear implant from a top surgeon at a renowned New York hospital and pairing it with a hearing aid in her other ear, she will still “guess at what's been said, and often get it wrong.” The extensive research is very current, almost all from 2010 and later. Ms. Bouton's entertaining writing style makes technicalities accessible to non-scientists. Particularly fascinating is the saga of the trip to Turkey which she thought brought on her first hearing collapse. She explains inductive loops, noise as a major cause of deafness (“the majority of hearing loss in America is noise-related”), the “ugly stepsisters” of tinnitus and vertigo, and assistive listening devices like FM systems. She presents cochlear implants, hearing aids and inner ears, although a few illustrations might have clarified them more.

Dementia and Regrowing Defective Hair Cells

As if hearing loss isn't enough to plunge us into isolation, anger and grief, recent research shows possible association between hearing loss and dementia. The author extensively interviewed researchers at many academic institutions, particularly Johns Hopkins University about the dementia connection and the University of Washington, where promising work on renewing damaged hair cells is progressing.

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For the hard of hearing person who thinks they are the only one so afflicted, each chapter concludes with “Voices:” interviews of others with sensory-neural hearing loss.

Ms. Bouton discovered a whole world of assistive devices and coping behaviors on joining HLAA. At the conventions of 2011 and 2012 she experienced loops and a congenial population of others who do not hear well.

This book should be in every public and medical library, in audiologists’ offices, and publicized at meetings of HLAA and other support groups.

Until profound hearing loss forced her retirement, Janet McKenna was a reference librarian at the North Tonawanda, NY, Public Library for 34 years. She still could hear the late Rocky Stone introduce his new support group, Self Help for Hard of Hearing People, at the American Library Association convention in 1982. Joining at once, she says, “SHHH (now HLAA) saved my sanity.” Mrs. McKenna now uses two cochlear implants and belongs to the Rochester, NY HLAA chapter.



Janet McKenna, MLS

This article is a condensed review of the book *Shouting Won't Help* by Katherine Bouton: One Woman's Experience of Going Deaf. This review was originally published in *Hearing Loss Magazine*, copyright 2013 Hearing Loss Association of America (www.hearingloss.org) and written by Janet McKenna, MLS.

DePaul awarded funding for Rochester View Apartments project

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NCDHR HAPPENINGS

Previously, in the February edition of *Healthy Signs*, it was announced that NCDHR had supported an application, by DePaul, to the NY State Housing and Community Renewal for the establishment of the Rochester View Apartments. (To read the full article, [click here](#)).

Earlier this month, DePaul was awarded funding for the Rochester View Apartments project. This project is part of the Governor's \$91 million initiative to build affordable housing in regions throughout the state. Low-income housing tax credits are connected to this project.

The Rochester View Apartments housing community will be located in Henrietta, New York. The site is designed with enhancements for people who are deaf or hard of hearing or who use sign language. This residential community is created to be deaf-friendly and inclusive, but, the community will not be exclusive to those who are deaf. The site will contain 60 affordable housing units with open floor plans with high

levels of visibility, safety lights (including strobe lighting for fire and carbon monoxide safety), video doorbells, video conferencing and calling, and pillows that vibrate during a fire alarm.

Case management services provided through the New York State Office of Mental Health will be available, on-site, to tenants, as needed. In addition, this site will serve as a satellite location for a PACE (Program of All-inclusive Care for the Elderly) program and will have social support and activities offered by the Rochester Recreation Club for the Deaf.

Construction of this residential community is scheduled to begin in the fall of this year. The opening date for residents is anticipated to be in the fall of 2014.

The Democrat and Chronicle also wrote an article about this recent accomplishment. To read the full article, [click here](#).



Photo compliment of <http://www.swbr.com/portfolio/depaul-rochester-view-apartments>

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Completion of the Preventive Cardiology Fellowship

Dr. Tamala David

At the end of July, 2013, Dr. Tamala David will complete her 2-year long Post-doctoral fellowship in Preventive Cardiology in the Department of Public Health Sciences at the University of Rochester. During her fellowship period, Dr. David engaged in several activities to increase public awareness about the health, safety, and quality of life needs of deaf, older adult sign language users and she acquired the additional training she needed to advance her career as a researcher.



Dr. Tamala David

During her first year as a post-doctoral fellow, Dr. David took classes to increase her knowledge and understanding about epidemiology and the healthcare system in the U.S. Then, she presented her earlier (PhD dissertation) research about barriers to health risk assessment among deaf and hard of hearing young adults at a national conference for the American Heart Association in San Diego, Ca. Finally, she wrote and submitted a career development grant proposal to the National Heart, Lung, and Blood institute at the National Institutes of Health with the hope of securing funding to conduct research on the topic of cardiovascular disease risk factors and social support networks among community-dwelling deaf, older adult sign language users.

During her second year as a post-doctoral fellow, Dr. David worked with her mentors and other researchers from the NCDHR to prepare research articles for publication and to plan future research projects. Additionally, she worked with Gillian Conde, from DePaul, the Rochester Deaf community, and other supporters to prepare and submit a grant for the Rochester View Apartments project to New York State. During the summer of 2013, she will work with Dr. Michael McKee and several summer interns to conduct the Deaf Seniors' Perceptions study; a study about the health of deaf, adult, sign language users age 65 and older.

Upon completion of her fellowship, Dr. David will continue to teach community health nursing to students at The College at Brockport, SUNY and hopes to continue her work as a researcher with the NCDHR.



NCDHR is very excited and grateful for everything Tamala has done during her stay here. NCDHR congratulates Tamala on her completion of the Preventive Cardiology Fellowship and wishes her luck in her future endeavors!

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NCDHR HAPPENINGS

The Farm Stand Returns

Set to kick off July 6



When: Saturdays, July 6 - September 7
10am-1pm

Where: Rochester Recreation Club for the Deaf
1564 Lyell Ave.

**Food cooking demonstration
July 27th,
11am-12pm**



Farm stand will be open every Saturday from 10am-1pm, July 6 - September 7. Check the [NCDHR website](#) for updates and more information!

Come buy fresh fruits and vegetables from local farms!

For more info or to volunteer, contact Kelly_Matthews@urmc.rochester.edu



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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This newsletter was supported by Cooperative Agreement Number U48-DP-001910 from the Centers for Disease Control and Prevention (CDC). The findings and conclusions in this newsletter are those of the author(s) and do not necessarily represent the official position of the CDC.