

## **HLAA-NJ NEWS, VIEWS & DATES – SEPTEMBER 2015**

***By Joel Strasser, APR, Fellow PRSA, Trustee and Public Information Officer, Hearing Loss Association of New Jersey (HLAA-NJ)***

### **Advocacy News and Results**

#### **HLAA Expresses Outrage at CDC Omission of Hearing Loss as Recognized Disability**

A new study published by the Centers for Disease Control and Prevention (CDC), while stating that one out of every five adults has a disability, went on to effectively ignore the 48 million Americans currently recognized as having varying degrees of hearing loss. Quickly noting this egregious omission, HLAA has taken action with both the White House and the CDC to see that swift and meaningful steps are taken to correct this gross error.

The study, entitled, "[Prevalence of Disability and Disability Type Among Adults, US, 2013](#)," examined vision loss, cognition, mobility, self-care and independent living, but failed to study hearing loss. In so doing, the CDC ignored 48 million Americans with hearing loss.

In the CDC's own words, "Understanding the prevalence of disability is important for public health programs to be able to address the needs of persons with disabilities."

Excluding people with hearing loss is not giving serious consideration to hearing loss as a disability that has an impact on a person's quality of life, ability to work, and to fully participate in society.

#### **Hearing Loss is a Major Public Health Issue, Third Most Common Behind Arthritis and Heart Disease**

- Hearing loss has been shown to be linked to an increased risk of falls, dementia, depression and other conditions that lead to a poor health status, according to Frank Lin, M.D., Ph.D. of Johns Hopkins University School of Medicine and Bloomberg School of Public Health.
- 20 percent of people in the United States, 48 million, report some degree of hearing loss.
- U.S. Department of Health and Human Services specifically includes people with hearing loss in their guidance on standards of data collection for people with disabilities, which CDC chose to ignore.

- In 1988, Congress authorized the formation of the National Institute on Deafness and other Communication Disorders, National Institutes of Health (Public Law 100-553), to conduct research and training on hearing and communication disorders.
- Under the Americans with Disabilities Act of 1990 (ADA), hearing loss is recognized as a disability that substantially limits a major life activity, and provides guidelines for communication access such as Telecommunications Relay Services, established under Title IV of the ADA.
- The CDC itself devotes an entire section of their website to children with hearing loss and includes research papers on adults with hearing loss.

“People with hearing loss have been denied communication access in hospitals and doctors’ offices, and by public programs such as Medicare which does not currently cover the cost of hearing aids,” said Anna Gilmore Hall, executive director of HLAA. “The release of the report comes on the heels of celebrations surrounding the 25th anniversary of the Americans with Disabilities Act, and we are stunned they failed to understand the impact of excluding hearing loss as a disability that needs to be addressed.”

## **Your Response Was Overwhelming! The CDC is Listening**

On August 7, 2015, Hearing Loss Association of America (HLAA) issued an action alert (above) regarding that recent CDC study, which excluded people with hearing loss.

And, your collective response was overwhelming! Consumers and professionals alike are aghast at the exclusion of people with hearing loss in a study administered by CDC. The responses we received were compelling, heartfelt stories of what it really is like living with a hearing loss:

- One advocate in New York wrote, “We need to take hearing loss in the United States from the realm of invisible, often ignored and still too often regarded as a shameful or embarrassing personal affliction to the forefront of major public health concerns.”
- “We can't fix that which we fail to see,” wrote one teacher.
- A consumer in Virginia said, “Given how this report will be used by federal, state, and local governments, as well as by other organizations to help them make decisions about funding and other issues to support the disability community, I really think you need to meet with the people at the Hearing Loss Association of America and listen to what they have to say.”

CDC itself notes in this study, “Understanding the prevalence of disability is important for public health programs to be able to address the needs of persons with disabilities.”

In a call with CDC, HLAA discussed that the study is part of a collaborative project

among all the states in the country and CDC, and is administered and supported by CDC and conducted via phone. The objective is to collect uniform, state-specific data on preventive health practices and risk behaviors that are linked to chronic disease, injuries and preventable infections diseases that affect the adult population.

HLAA made it clear to CDC that we had received a strong response from our community. We told them that it's vital that public health programs have access to data that includes people with hearing loss. CDC heard our message.

***Now, the door has been opened***, thanks to your overwhelming show of support. CDC is listening. HLAA will continue to talk and to listen to CDC as well. We appreciate that CDC has been responsive to our request and has opened up a dialog with us. HLAA will continue to work with CDC. We know that data regarding the health needs of people with hearing loss is sorely needed. We see this as just the first step to ensure that people with hearing loss are counted and there are voices heard.

### **Chapter News for September**

**HLAA-Essex County Chapter** – For the first time in recorded history, HLAA-Essex County Chapter and the New Jersey Chapter of the Alexander Graham Bell Society will hold a dual, joint meeting on **Saturday, September 19, 2015**, when they open their Fall 2015 KickOff Meeting at the Maplewood Memorial Library's Memorial Hall, 51 Baker Street, Maplewood, NJ, from 12 Noon to 3 PM. Three speakers at the meeting will include Dr. Kathleen Delaney, Au.D., CCC-A, FAAA, from St. Barnabas Health Care System; Dr. Leslie Herman, Au.D., CCC-A, FAAA, from Summit Hearing Aid Center, speaking on the role of the audiologist. Also, Dr. Justin S. Golub, MD, assistant professor of otology, neurology and the Skull Base Surgery Department of Otolaryngology-Head and Neck Surgery, Columbia University College of Physicians and Surgeons, New York-Presbyterian/Columbia University Medical Center, will speak on cochlear implants – What they are they, what happens during surgery, and what happens after surgery???

**HLAA-Morris County Chapter** will meet **Saturday, September 12th** at the Summit Speech School at 705 Central Ave, New Providence, NJ. They will have Coffee and Conversation from 10:00 AM to 10:30 AM as a great way to make new friendships. Meeting from 10:30 AM to 12:30 PM. Please note that this is a recently-changed location from many meetings held earlier this year.

Special guest will be Debby Schaser, owner and founder of Canine Hearing Companions, Inc., of Vineland, NJ. She has been training hearing dogs for the past 22 years, with the active help of local federal prison inmates, and can also talk about therapy dogs that help returning war veterans suffering from PTSD and also make hospital visits, clinical dogs, crisis dogs and others. She usually brings one of her trained dogs to demonstrate what they can do. Mark your calendar prominently for this special program on September 12th.

In addition, Morris County seeks to attract 18 - 35 year olds so they can start their own group. Please pass this information on to anyone in that age group. Questions may be directed to Pat.Dobbs@HLAA-NJ.Org.

**HLAA-Middlesex County Chapter**, which meets every 3rd Tuesday each month from September to June, except July or August, meets next on **Tuesday, September 15th**, 7:30 pm, First Baptist Church of South Plainfield, 201 Hamilton Blvd., South Plainfield, NJ 07080. This meeting will feature a roundtable discussion of the program year ahead, a review of available assistive listening and hearing technology devices, a discussion of plans for the October Walk4Hearing, and a report of what transpired at the August 30 Walk4Hearing KickOff event. The meeting room is looped and may also include a sign interpreter as well as a CART reporter.

**HLAA-South Jersey Shore Chapter** will meet **Thursday, September 17th**, 5:30-8pm, at Cape Regional Medical Center, 2 Stone Harbor Blvd., Cape May Court House, NJ 08210. GSP to Exit 10.

**HLAA-Bergen County Chapter** will not meet in September, but welcomes contact from interested potential members and leaders, who are invited to contact Ken Keuhlen at [kbk1011@hotmail.com](mailto:kbk1011@hotmail.com)

### **Other Meetings of Note and Interest**

**Ocean-Monmouth Hearing Loss Support Group's** next meeting is **Sunday, September 27th** at 1:30pm at the Manalapan Library, 125 Symmes Drive, Room 7, Manalapan. Special guest will be Jamie Sklarski, Au.D., CCC-A, Northeast Regional Cochlear Implant Consumer Specialist for Advanced Bionics, LLC, who will discuss cochlear implants and the exciting new technology advances now available. During her presentation, Dr. Sklarski will describe cochlear implant systems, discuss who comprise the most appropriate candidates, describe their benefits vs. hearing aids, talk about the requirements and qualifications for CIs, and discuss the current state of today's CI technology. She received her Au.D. degree from the University of Buffalo in 2009, and has extensive clinical experience working with cochlear implant recipients and their families. Her background also includes Music Therapy training for which she received her bachelor's degree from the State University of New York at Fredonia in 2004.

**Meridian Health Workshop**, "Take Control of Your Health," (Living Well with Chronic Conditions), Friday, September 11 through Friday, October 16. Program designed for, but not limited to, deaf, deaf-blind, hard of hearing, chronic health condition(s), depression. Caregivers are welcome to attend. Designed to help attendees gain confidence with ability to manage health and overcome daily challenges. Meets once a week for six weeks, at Jackson Health Village, 27 S. Cooks Bridge Road, Jackson, NJ

08527. For further information, contact the leader: Jessica Ansbach, NIC, [jansbach@meridianhealth.com](mailto:jansbach@meridianhealth.com), or 732-751-3586.

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### **Walk4Hearing Date, Walk Details and How to Contribute**

**Sunday, October 18, 2015** – Walk4Hearing: Mercer County Park, Hughes Drive, West Windsor and Hamilton, NJ, 10 AM, Registration and Check-In; 11 AM, Walk begins.

Walk4Hearing events are fundraising 5K (3.1 miles) walks held across the United States. Since its formation in 2006, Walk4Hearing has raised over \$9 million dollars for programs and services for people with hearing loss, and has grown into the largest awareness and fundraising event for the Hearing Loss Association of America® (HLAA). Collaborating with local HLAA chapters, Walk4Hearing educates the general public about hearing loss while easing the associated stigma. Striving to make hearing loss a public health issue, thousands of people of all ages, races, and backgrounds have come together to display their compassion for the cause and to make hearing loss an issue of national concern. For further details about the HLAA-NJ Walk, contact Wayne Roorda at [bigbearnj@gmail.com](mailto:bigbearnj@gmail.com)



### **HOW to Contribute:**

**Be Sure to Correctly Designate Your Intended Walk Beneficiary**

If it's the donor's intention to benefit people with hearing loss **inside** the State of New Jersey, it's important to understand the importance of registering correctly. Donors first choice should be to designate "HLAA New Jersey State Association," as 50% is shared with HLAA National (which is what happens with any designation) - and 40% would go to HLAA-NJ. Also, as there are other alliance teams, those are listed for people who already know specifically whom they're designating their 40% proceeds for. All others, or just anyone wanting to participate in the NJ Walk4Hearing should be selecting HLAA New Jersey State Association if they are not specifically intending to donate to any other group. In prior years, some Walk funds did not go to donors intended beneficiaries because they were not correctly designated during the registration process.

Walk checks should be made payable to "NJ Walk4Hearing." It is important for each donor to carefully select what gets checked off when registering to participate in the Walk. On the first online page, there's a dropdown list of "alliance teams". HLAA New Jersey State Association is listed first - and unless people are walking for specific other causes (like AGBell, or Summit Speech School), then they should choose HLAA-NJ. There is also a category, "HLAA National," which may have misled donors in prior years. When a donor checks off HLAA National, 90% goes to HLAA National and nothing goes to benefit people with hearing loss inside the state of New Jersey, or HLAA-NJ at the state level. So, it becomes critically important, both prior to the Walk, and definitely on the day of the Walk, for donors to make the correct designation. It's only after all the money is collected, either by check or credit card, that it is divided up according to the category specifically designated by each respective donor.

### **NEWS from HLAA-NATIONAL:**

### **SAY THANKS for hearing access every chance you get!**

The Sarasota and Manatee Chapter's photographer, Robert Schuler, added a new twist to the photos that he takes at every monthly chapter Movie Club outing. He invited the Regal Theatre customer service rep, Rich Goddard, to join some members so they could express their gratitude for the Sony Caption Glasses which all Regal Entertainment Group theaters in the country offer. It is simple but powerful to say thanks to any venue that offers a hearing access system to support

us. Sharing the photo with the rest of the membership on Facebook or in the newsletter is a great way to remind other members that thanking the staff for their loop, captions or CART can go a long way in promoting more hearing access in the community. September is HLAA's 35th Anniversary Movie Month during which HLAA will be encouraging every chapter to organize a movie night for their members and the community. Every chapter leader should make sure they have tried the Sony Caption Glasses or the CaptiView system at their local theaters well in advance so you can guide your chapter members. To learn what captioned movie houses are near you and what their weekly showing schedule is, go to [www.captionfish.com](http://www.captionfish.com).



### **Friends in the community help build chapters**

Some chapters have found an easy to use, no-cost away to build awareness and interest in their community. It's called Facebook and it can make more people aware of your chapter mission, programs and meetings than most chapter newsletters and emailing campaigns combined. One reason that the Lakeland (FL) Chapter has become such a very strong chapter in such a relatively short time is because it is #1 on the HLAA Top Ten Chapter list this year with more than 900 friends despite being a relatively new chapter formed some four years ago. The Essex County (NJ) Chapter is another case in point, as it is one of the fastest growing new chapters in the nation and is attracting a lot of young people. It was only formed in February, but has had meteoric rise on Facebook, as it now ranks #5 on the HLAA Chapter Top 10 list. Fifty-five chapters or state organizations have a Facebook page and 21 more host one for their WALK. If your chapter is not getting the most out of your current Facebook page, or you would like to start one, check with leaders of the Essex County (NJ) Chapter.

### **AN OPEN LETTER TO ALL READERS FROM**

# NEW JERSEY'S ONLY FINALIST



Dear Members and Friends:

As you may know from other sources, Oticon has selected me as one of their national Focus on People finalists, and as of right now they have opened online public voting that continues through September 18. If the total online vote count results in my achieving their first place position, Oticon will make a donation of \$1,000 to HLAA-NJ. I think it's also important to note that I am the only finalist from the State of New Jersey.

If you have any way of helping me spread the word publicly, through any of your collected membership, mailing or distribution lists, I'd very much appreciate your help. Of course, I'd very much appreciate your casting your own personal vote, in addition to encouraging those of others, as described below. If you need additional paper copies of these voting instructions, please let me know at [joel.strasser@hearingloss-nj.org](mailto:joel.strasser@hearingloss-nj.org). And, please feel free to make additional copies to distribute or hand out.

Here's the best link to vote from, and also to circulate: <http://www.oticonusa.com/about/people-first/focus-on-people/nominees/j-strasser.aspx>

Remember, anyone can vote -- that's anyone with an online computer. And, when it's all over, it will be the total number of online votes that determines the first place winner, and I would like to be that person in Oticon's Advocacy Volunteer category.

As the competition involves open and public online voting by untold numbers of total strangers with access to computers, please feel free to share this information as broadly as you feel appropriate. Many thanks for your help.

All best regards,

*Joel*

Joel Strasser

**Oticon's official press release follows below:**

**Vote for Joel Strasser in the 2015 Focus on People Awards!**

**Vote Online at [www.oticonusa.com/Vote](http://www.oticonusa.com/Vote) now through September 18**

**Oticon, Inc. has narrowed this year's finalists down to 9 outstanding people with hearing loss who are helping to change negative stereotypes of what it means to have a hearing loss.**

**Each is unique, remarkable and inspiring. And we are pleased to announce that Joel Strasser has been chosen as a finalist in the Advocacy category!**

**Joel, an award-winning PR executive and a person with hearing loss for more than 50 years, never tires of spreading news about hearing loss through local and national media. His work has resulted in numerous articles and news reports that help to dispel negative perception, influence decisions makers to enact legislation and create more auditory accessibility for people with hearing loss.**

**Please help us recognize Joel as one of the top finalists by casting your vote at [www.oticonusa.com/Vote](http://www.oticonusa.com/Vote).**

**This is the 17th year that the Oticon Focus on People Awards has honored hearing impaired students, adults and advocacy volunteers who have demonstrated through their accomplishments that hearing loss does not limit a person's ability to make a positive difference in the world.**

**We encourage you to read all of the stories from this year's finalists. Our goal is to help Oticon reach as many people as possible with the inspirational stories of the Focus on People Award finalists.**

**Please share this note with your family, friends and anyone you think would enjoy reading about the accomplishments of some remarkable people with hearing loss who show that hearing loss does not limit a person's ability to achieve, contribute and inspire.**

**And please encourage them to vote for Joel Strasser!**

**Voting closes on September 18. Winners will be announced in October.**

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