

HLAA-NJ NEWS, VIEWS & DATES – OCTOBER 2015

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

Let's Walk4Hearing on October 18; Here are Walk Details, How to Contribute



October's biggest HLAA-NJ activity in New Jersey is our annual Walk4Hearing, to be held Sunday, October 18, 2015 at Mercer County Park, Hughes Drive, West Windsor and Hamilton, NJ. Registration and Check-In start at 10 AM, and the walk begins at 11 AM.

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



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.

Advocacy News and Results

Anna Gilmore Hall Updates HLAA-NJ re CDC's Omission of Hearing Loss Disability, Cites CDC Steps of Recent Weeks

"Nice to hear from you. I am sorry it has taken me so long to respond back to you, but we were waiting for a couple more pieces of information from CDC. CDC has been open to our suggestions and we feel while not all issues have been resolved, we are

making a good start. Below is a summary of what has happened over the last few weeks.

“In August, when the Center for Disease Control and Prevention (CDC) issued the results of a survey that for the first time asked questions about disabilities, we were stunned to find that people with hearing loss were entirely left out.

“HLAA sent out letters to CDC, to the White House, issued a press release and an action alert asking consumers to express their thinking of CDC’s survey. Many of our members sent in emails with compelling stories, making it clear we should have been counted from the start.

“As a result, CDC contacted HLAA. We learned that CDC has been working for years with states to collect health care data under the Behavioral Risk Factor Surveillance System (BRFSS) survey. In **2013**, for the first time, CDC included questions regarding disability in BRFSS. They tell us that they excluded people with hearing loss because the survey is done via telephone; they were concerned that the population of people with hearing loss would be undercounted as a result of their collection method.

“We find this unacceptable. Clearly, people with hearing loss have access to telephones; cell phones, captioned phones, VRS and even the old TTY’s. In addition, had they been truly concerned that people with hearing loss do not own phones, they could have changed the data collection method. Instead of underrepresenting us, they chose not to count us at all, rendering us invisible once again.

“In our talks with CDC, we were asked to write a letter of support for inclusion of a question on hearing loss in upcoming surveys, which we provided. We have since learned that there will be a question seeking to find people with hearing loss in the 2016 survey. It is a start.

“However, the question that was approved, “Are you deaf or do you have a significant hearing difficulty” does not go nearly far enough. If you are a public health official trying to tease out information about the health of your community, one would think it would make sense to make the most of the opportunity. It just makes sense to learn whether health care needs of residents who are deaf are different than those who have a hearing loss.

“HLAA also asked that CDC’s marketing materials for this survey makes it clear that until 2016, they only have a piece of the picture of health in the disability community. (Surveys done in 2014 and 2015 did not have the hearing loss question). We asked to be part of a cross-disability advisory council to ensure that mistakes like this never happen again. It has been said before, and truly is applicable in this case, “nothing about us without us”. This would never have happened had we been there when decisions were being made.

“We are continuing to work with CDC. They have been open to our suggestions and we feel while not all issues have been resolved, we are making a good start. We have our members to thank for that. Their voices are being heard.”

- Anna Gilmore Hall, Executive Director,
Hearing Loss Association of America

Chapter News for October

HLAA-Morris County Chapter, on **Saturday, October 3rd**, will have a booth at Madison, NJ's Bottle Hill Day, Madison's annual fair. It's a lot of fun, very well attended, and all are invited to come and join the festivities.

In addition, HLAA-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.

Also, looking ahead, HLAA-Morris County's next meeting is on **Saturday, November 7**, 10:00 to 10:30 am, Coffee and Conversation, and 10:30 am to 12:30 pm for the meeting. Location will be the Summit Speech School, 705 Central Avenue, New Providence, NJ. CART captioning will be provided by the NJ Dept. of Deaf and Hard of Hearing, plus there will also be Assistive Listening Devices. Chapter president Pat Dobbs will speak on “Traveling Adventures with Hearing Loss,” describing how she dealt with her hearing loss while traveling recently in Alaska and the Yukon, including camping out alone at night.

HLAA-Middlesex County Chapter, which meets every 3rd Tuesday each month from September to June, except July or August, meets next on **Tuesday, October 20th**, 7:30 pm at the First Baptist Church; 201 Hamilton Blvd.; South Plainfield, NJ. Brenda Miers, LSW, a counselor with the Center for Family Services program Recovery Network for Deaf, Hard of Hearing and Hearing Loss is coming to do a presentation at this meeting. She has been providing services in north and central Jersey. She has been working mostly with the Deaf and wants to reach out to others with hearing loss. She will provide CART and a sign interpreter mostly for her own use so she will make sure to hear questions from the members. We will have the room looped as well with assistive listening devices for those without telecoils. We will be participating in the NJ walk4hearing for the 8th straight year as Edy's Angels team. The walk will take place before the meeting so will have a recap of the event.

HLAA-South Jersey Shore Chapter will meet **Thursday, October 15th**, 5:30-8pm, at Cape Regional Medical Center, Maruchi Room, 2 Stone Harbor Blvd., Cape May Court House, NJ 08210. GSP to Exit 10.

HLAA-Essex County Chapter – No meetings scheduled for October; please stay tuned for news of our upcoming activities in November.

HLAA-Bergen County Chapter will not meet in October, but does plan to meet in November. The chapter welcomes contact from interested potential members and leaders, who are invited to contact Ken Keuhlen at kbk1011@hotmail.com

Other Meetings of Note and Interest

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, or 732-751-3586.

NEWS from HLAA-NATIONAL:

ADVOCACY

PCAST

HLAA has submitted written comments to the President's Council of Advisors on Science and Technology (PCAST). PCAST is an advisory group of the nation's leading scientists and engineers who directly advise the President and the Executive Office of the President. The Council makes policy recommendations in the many areas where understanding of science, technology, and innovation is key to strengthening our economy and forming policy that works for the American people. On September 18, the Council discussed how technologies and policies for hearing aids affect older Americans. Lise Hamlin, director of public policy at HLAA provided recommendations to the Council on behalf of HLAA. In addition to our recommendations, HLAA has provided our most recent policy statements to the committee – "Screening for Hearing Loss in Primary Health Care Settings," "Wider Access to the Full Spectrum of Hearing Technology Benefiting People with Hearing Loss," "Medicare Coverage of Hearing Aids and Aural Rehabilitation," and a policy paper by Dr. Margaret Wallhagen titled "Hearing Loss: Impact, Policy Implications, and Future Directions." The archived webcast will be available soon:

<http://www.tvworldwide.com/events/pcast/150918/>

Written comments to PCAST may be submitted at any time to pcast@ostp.gov.
<https://www.whitehouse.gov/administration/eop/ostp/pcast/meetings/future>

The National Academies of Sciences, Engineering and Medicine's Forum on Aging, Disability, and Independence will hold a public workshop all day on Tuesday, October 6 at the Keck Center in Washington, DC, on maximizing independence and promoting community living for older adults and people with disabilities. The forum is open to the public. HLAA will be attending. The registration link is below.

<http://www.surveygizmo.com/s3/2279213/Forum-on-Aging-Disability-and-Independence-Public-Workshop-October-6-2015>

Hearing Health Forum on Capitol Hill

Friends of the Congressional Hearing Health Caucus (CFHHC) of which HLAA is an active member is hosting a Hearing Health Forum and Reception on Wednesday, October 21. The forum is open to the public. Representatives David McKinley (R-WV) and Mike Thompson (D-CA) will be honorary chairs of the event. Hearing screenings, earbud noise testing and professional advice will be available to attendees during the forum. Please RSVP to Matthew Jones at mjones@bostrom.com or 202.712.9050 if you would like to attend.

DEVELOPMENT

The Combined Federal Campaign (CFC) National Capital Area conducts fairs during the September 1 through December 15 giving period. HLAA will participate in the Department of Defense event at the Pentagon on Thursday, October 29. It's a great opportunity to meet present and potential donors in one place. Remember if you participate in the CFC, designate #11376 as your charity of choice

PUBLIC AWARENESS

HLAA Board Chairperson, Dr. Margaret Wallhagen spoke Friday, September 18 at the National Center for Rehabilitative Auditory Research conference "Hearing Loss as a Public Health Concern." Her session discussed primary care models for promoting hearing health care and access.

CONVENTION

The Call for Papers has officially opened for HLAA Convention 2016 and IFHOH Congress, a joint event expected to bring 2,200 people to the nation's capital, June 23-26. Interested in presenting a workshop? Go to <http://bit.ly/CallforPapers-EducationTracks> to submit your proposal. Deadline is Friday, December 4, 2015.

Proposals for State/Chapter Development workshops must be submitted using a special form available from HLAA National (see their website).

Deadline for all proposals is **Friday, December 4, 2015**.

Registration for Convention

State and Chapter Leaders, again this year you can receive 4 discounted registrations for leaders **PLUS** one delegate registration which might be considered for someone being readied for a leadership position. Also, keep in mind that registrations will not be processed unless we have received a current State/Chapter Update Form on file.

See

hearingloss.org/sites/default/files/docs/Chapter_State_Update_Form_fillable_v2.pdf

CHAPTERS

Roger Pen Free Trial Program

Sixty chapters are participating in Phonak's Roger Pen Program that allows chapter members to provide feedback about these wireless devices to the manufacturer. All chapters participating in this program should remind all participants to complete the online survey: surveymonkey.com/r/PhonakRogerPen following use of the device.

Cruises offering hearing access supported vacations

Last call for the week-long Caribbean cruise leaving Ft. Lauderdale on November 8, 2015. Contact Lynn Rousseau at lynnrousseau50@gmail.com.

HLAA Members in Texas has announced a May 22-29, 2016 Western Caribbean cruise from Galveston to Roatan, Honduras; Puerto Costa Maya and Cozumel both in Mexico, on the RCCL The Liberty of the Seas. The cruise includes an access-supported Broadway show, Ice Show and 3D movies plus a surf simulator, rock climbing and much more. For details, email dkerper@cruiseplanners.com.

Chapter Coordinators Wanted

State Chapter Coordinators play a vital role in coordinating support from HLAA for the chapters. HLAA would like to provide more state coordinator coverage; if you are interested in learning more about the position and opportunity, email Ed Ogiba at eogiba@hearingloss.org.

PERSONNEL

Susan Parras, HLAA director of web technologies since 2008, has departed from HLAA; September 11 was her last day. We are sad to see her go and wish her continued success in her career. The staff held a lunch sendoff and presented her with a Thank You gift for her many years of service to HLAA. She, in turn, thanked the staff for the opportunity and says she will continue to refer people to HLAA. Many things happened during her tenure, among them, a redesign of the HLAA website hearingloss.org and the launch of the Walk4Hearing website and team raising software. We are currently recruiting for this position and hope to have a qualified web manager in place as soon as possible.

HLAA is also continuing to recruit for a Director of Marketing and Communications as well as Controller.

CAPTIONED TELEPHONE SURVEY

In recent weeks, HLAA-National sent out a survey on IP CTS (Internet Protocol Captioned Telephone Services). The information from this survey will be used to help the FCC understand how individuals are using captioned telephones. At this writing, we have received more than 300 completed surveys. The survey is still open, so if you haven't responded and use captioned phones, please do give us your feedback. If you would like to participate in this online survey, go to <https://surveys.mitre.org/content/ipcts2/>.

Want younger members? Get a young leader.

One of the top five questions chapter leaders ask is "How do we attract younger members?" The adage that "*birds of a feather, flock together*" is advice that the Essex County Chapter (NJ) takes to heart as they sent one of their young leaders to his first day of high school on a chapter awareness building mission to attract more young people to the chapter. Shown below is Rashaun Simpson armed with Walk4Hearing brochures to share with his classmates on the first day of school. If you want to attract young people, you need to hold events that appeal to them, which is one of the added benefits of getting involved in the Walk4Hearing! It always brings out a young crowd.



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. Congratulations, Latisha!!!

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