

# HEARSAY

The Official Newsletter of Hearing Loss Association of PA

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## MESSAGE FROM DIANA

### Message from Diana

According to the National Center for Health Statistics there are now thirty-six million Americans who have some level of hearing loss making hearing loss a health condition that's topped only by heart disease and arthritis. On September 26, 2009 HLA-PA will sponsor the PA Walk4Hearing event in Ridley Creek State Park, Newtown Square, PA. Our walk is one of 22 walks being held throughout the nation this year. We are walking to create public awareness about the prevalence of hearing loss and to eliminate the embarrassment and stigma that prevent

people from seeking help in adjusting to hearing loss. The funds raised are used to promote captioning, accessible mainstream products and services, scholarships, insurance coverage, employment and education rights and national and local services for people with hearing loss. We welcome all who wish to join us in the walk to focus attention nationwide on hearing loss: prevention, regular screening, treatment options, and how to live with it successfully.

Diana Bender,  
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## Pennsylvanians recognized at the HLAA Convention in Nashville, TN

On Sunday, June 21 four Pennsylvanians were honored at the HLAA Awards Ceremony that took place at the Gaylord Opryland Convention Center in Nashville, TN. Michael Stone, President of the HLAA Board of Trustees, presented the prestigious Keystone Award to Henry Fader, a longtime member of the HLAA Board of Trustees, for his outstanding contribution to the continued success of HLAA. Mr. Fader's name will be inscribed on a plaque at HLAA headquarters in Bethesda, MD.

Carolyn Meyer of Elkins Park, PA, a member of the HLA-PA Advisory Council, received the Advocacy Award for her work as a wonderful advocate for HLAA itself, in addition to all her efforts to advocate for issues such as hearing aid insurance coverage and airline access which are so important to people living with hearing loss.

Kathy Niemeyer, also a member of the HLA-PA Advisory Council, received the newsletter award for the Pittsburgh newsletter of which she is editor.

Barbara Beard of Hershey was recognized for her 3 years of service as our Central PA chapter coordinator. Barbara held this position from 2005 until 2008 and worked closely with chapters in her region.

Congratulation to all our PA award winners!



## HLA-PA & Art-Reach Partner on Cultural Access

HLA-PA has started a new partnership with Art-Reach, a nonprofit organization that connects underserved audiences with the arts. HLA-PA is serving as a Community Partner on a new initiative Art-Reach is launching this fall called the Independence Starts Here Cultural Calendar.

Until now there has been no centralized way for audiences who are hard of hearing to learn about all the accessible events that are available to them. The Independence Starts Here Cultural Calendar is a one-stop resource for captioned cultural events, as well as those that feature audio description or American Sign Language interpretation. Maintained on the Philly Fun Guide, the region's go-to resource for entertainment and cultural events, the calendar lists all the events offering these services and allows audiences to quickly and easily purchase tickets. Art-Reach has also launched an email club for audiences who want to sign up for monthly ticket discounts and other special promotions. To see the calendar and join the email club, log on to [www.PhillyFunGuide.com/access](http://www.PhillyFunGuide.com/access).

The calendar features over 20 different events that demonstrate the richness and diversity of the Philadelphia cultural community. Cultural organizations and venues represented on the calendar include Amaryllis

Theatre Company, Arden Theatre Company, the Academy of Music, Enchantment Theatre Company, InterAct Theatre Company, Mural Arts Program, National Constitution Center, Opera Company of Philadelphia, Philadelphia Museum of Art, Philadelphia Theatre Company, Philadelphia's Magic Gardens, Scott Arboretum, Theatre Alliance of Greater Philadelphia, Walnut Street Theatre and the Wilma Theater.

The Cultural Calendar serves not only people who are blind or deaf but also those whose vision or hearing is deteriorating due to age or other factors. "There are many people whose enjoyment of the arts can be enhanced through services like captioning and audio description," Art-Reach Executive Director Michael L. Norris said. "We hope the calendar is as much a resource to them as the blind and deaf community."

As a Community Partner, HLA-PA is helping to build awareness of the new calendar within the hard-of-hearing community. Other Community Partners for the calendar include: Associated Services for the Blind and Visually Impaired, the Deaf-Hearing Communication Centre, the Pennsylvania School for the Deaf and the Philadelphia Corporation for Aging.

The Independence Starts Here Cultural Calendar is not only a great resource for audiences interested in accessible programming. It also serves cultural organizations by promoting their accessible events. As James Haskins, Managing Director of the Wilma Theater, says: "We'd like to find ways to increase the use of our services given the commitment we've made to being accessible." In addition to maintaining the calendar itself, Art-Reach is implementing a multi-layered marketing campaign to build awareness and drive audiences to the Fun Guide. This campaign will include direct-mail, advertising and media relations, along with

grassroots distribution and word of mouth. Printed pieces for the campaign will also be accessible, featuring Braille and large-print type.

"We hope that more cultural organizations will want to provide these types of accessibility services once they see everything we're doing to increase awareness and build audiences," Norris said. "And in addition to Art-Reach's marketing efforts, Independence Starts Here also helps cultural organizations to provide access since VSA arts of Pennsylvania now has an audio-description system and an open-captioning system that are designed to be shared across the community and can be rented at little or no cost."

The Cultural Calendar is part of a larger initiative, also called Independence Starts Here, on which Art-Reach has partnered with VSA arts of Pennsylvania since 2004. "The whole initiative works on two tracks," said Norris. "One is helping cultural organizations to become more accessible; the other is to build audiences for accessible arts events. VSA arts of Pennsylvania leads the first track, and Art-Reach, which has been connecting audiences to the arts for over 23 years, leads the second. The new Cultural Calendar is a great way for Art-Reach to build awareness and audiences for accessible cultural events."

The Independence Starts Here Cultural Calendar is made possible through the support of the Greater Philadelphia Cultural Alliance. Additional support provided by PNC Arts Alive, the Samuel S. Fels Fund, the Christian R. and Mary F. Lindback Foundation and individual Art-Reach donors.

*Submitted By Michael L. Norris* [www.art-reach.org](http://www.art-reach.org)

## Grandmom and Me and the System

Several years ago a woman, who had lost her hearing late in life, told me she felt that her teenage grandchildren were uncomfortable with her hearing loss and were avoiding talking with her. She was disappointed when she could not find a book written for teenagers that explained hearing loss and how they could better communicate with her. Her sadness about it haunted me, and I decided that one day I would write a book.

Now I have grandchildren of my own, and I recently came to realize that I had been pretending to them that I heard what they were saying, when actually I had no clue. That realization was the motivation that encouraged me to write Grandmom, and Me, and the System.

Even though I am completely open with adults about my hearing loss, I went back to my old ways of denying it when it came to my grandchildren. I felt for myself the disappointment of that woman who longed for a better relationship with her grandchildren. So I considered the most difficult times for me when interacting with them, as well as the times that I detected confusion or disappointment in their faces when my responses did not fit in with the conversation, and I wrote a story, which is for very young children, that tells of ways that relationships can be more loving and fun when hearing loss is involved.

I was joyfully surprised when I used my book to explain to my grandchildren what I needed, and found that they had such an interest in my hearing loss, my hearing aids, and in learning how to use the System.

I sincerely hope that my book will help other hard-of-hearing people preserve a close relationship with their young family members.

To order the children's paperback book, Grandmom, and Me, and the System, send a check or money order for \$7.00 (which includes the cost of the book plus postage), to Peg Adamucci, 7 N. Columbus Blvd., Unit #244, Philadelphia, PA 19106. Please be sure to include your name and address!

## Follow-Up: Hearing Loss Harms Marriages

The following are some responses to the Hearing Loss Harms Marriage article that we printed in the March issue of this year. We continue to welcome and encourage more responses. Maybe you have a recurring incident as the women below share, or maybe there was one incident that occurred and now you may be able to laugh about it or you have learned from it. It has been helpful for people to know that they are not the only ones having issues with communication because of hearing loss in relationships.

Please share your experiences: [baf@fast.net](mailto:baf@fast.net)  
*Beth Ann Rejonis, Editor* Having read the excellent article on the effect of hearing loss on marriages, I'm prompted to share my own experience. I lost all hearing in one ear abruptly over night - I went to bed with normal hearing and woke up fully deaf in one ear with the diagnosis of Sudden Sensineural Hearing Loss. My husband was sympathetic and caring and remains so but there are two areas of communication he finds difficult to change one is speaking to me when I'm on the phone. I can hear in one ear and need that ear for the phone but I cannot hear with the other ear. He will hear my conversation on the phone and respond - I can see his lips moving.... but unless I take the phone away from my ear, I can't hear what he's saying.

I've had to hang up on some phone calls as he's so insistently talking to me while I have the phone to my functioning ear. In the ideal

world, he would grab a piece of paper and a pen and jot down what he wants to say while I'm on the phone but this is one area where he cannot make the transition. No matter how upset I might get or how often I roll my eyes at him when he starts to speak to me when I'm on the phone, he continues to do it.

The other change he cannot make is shouting to me over distances in the house. He will call out something to me - I can only hear that he is saying something but I cannot with only one ear tell what he is saying over distances. I have to shout out to him "I can't hear what you're saying but I will come to where I can hear." And hopefully he will tell me where he is in the house as I have no ability now to locate sounds. I'd rather he'd just shout out "Can we talk and I'm in the living room" rather than go through the rigmarole each time of me saying "I can't hear but I'll come nearer so I can hear you.... uh, where are you exactly?"

Compared to the challenges of other hearing-impaired people, these are indeed small ones and I wouldn't want to seem complaining. So I'd also share stories about how helpful he is at other times. I need only to look at him in a restaurant when I haven't been able to tell what the waitress was saying and he knows that 'look' and quickly tells me what I missed. He always steps aside and asks others to do the same so I can have the seat at the table where I will be most able to hear.

We need to remember that challenges such as hearing loss can bring out the good things in relationships too.

*S. Matthews*

I am new at using the computer, but there is no stopping me now. I have been married 35 years, and have three children,

I am the only one with a hearing loss, and even though I have explained to my family what is like to be hearing impaired, and how hard it is, it falls on deaf ears (now that is a good one!). The way they take hearing for granted is appalling, and even though I cannot hear, I am a much better listener and remember what people say when I do understand.

One of the things I am tired of is that I do all the work. When I talk to them I always get up to their faces, when they talk to me many times they do it as they walk away, (I lip read) and this is just for starters. As you can see for being married for as long as I have, I would be able to contribute plenty of experience and information. Also at the present I am not happy in my marriage, especially since I still don't get compassion and understanding from my husband, and if you can believe this, he is suppose to be a heck of a nice guy.

So much for that!

*Anonymous*

### Telephone Contacts

For HLA-PA Activities or Other Information,  
feel free to call:

Teresa Nellans, (Western PA) - 412-767-9769

Barb Beard, (Central PA) - 717-534-0820

Ronnie Adler, (Eastern PA) - 610-644-3154

## HearSay Subscription

If you would like to receive your own copy of *HearSay*, the official newsletter of HLA-PA, please fill in this form and mail it to the address below. A *HearSay* subscription is free; however, HLA-PA is a not-for-profit organization run exclusively by volunteers and we are grateful for any donations.

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Enclosed is my contribution of \$\_\_\_\_\_ to support HearSay. Donations are tax deductible.

**Make donations payable to HLA-PA and mail to:**

**Marcia Finisdore  
HLA-PA  
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I would like to remain anonymous

I cannot contribute, but would like to receive HearSay.

## VOLUNTEERS NEEDED!!

Assist the HLA-PA State Director by serving on the Advisory Council or one of its committees. The Council meets periodically in Carlisle but committees conduct most of their business by e-mail and occasionally meet in various parts of the state. If you think you would like to serve on the council or any of its committees, please contact one of the state leaders listed here:

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## HLA-PA Donors

*A special thanks to those who help make it possible.*

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