

HEARSAY

Volume 2, No. 2 June 2003

THE OFFICIAL NEWSLETTER OF ...



SHHH opens the world of communication to people with hearing loss.

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Keep up-to-date. www.pa-shhh.org

A Message from Marcia

When the SHHH Board of Trustees developed the concept of a "state office" as part of the strategic plan, the goal was to increase recognition of SHHH on a state level. We are making progress toward this goal. We receive many more requests for information and service than in the past. These requests come from service agencies, other organizations, government offices, but mainly from consumers.

The bulk of the calls, letters, and emails from consumers relate to denial of access. Join me in applauding one of our members, Jack O'Keeffe from Aliquippa, PA, who "complained" because he was denied access.

Jack filed a complaint with the FCC because an emergency broadcast was not captioned. Not only was Jack's complaint answered by the FCC and the national network required to caption emergency announcements as required by law, but also he was asked to speak at an FCC conference!

It takes only one person to make a difference. Write a letter when you are denied access. Please respond to our requests for letter writing when important bills are before the state legislators. Without your help we will never reach our goal. Thank you.

Marcia Finisdore,
PA-SHHH State Director



c/o Marcia Finisdore, State Director
8 Azalea Lane
Media, PA 19063-2240

RETURN SERVICE REQUESTED



Look for this International Symbol of Access for Persons with Hearing Loss

From the Editor

According to the latest statistics I have, there are about 1,363,100 hard-of-hearing people in PA. These same statistics indicate that only about 273,000 own hearing aids. This means that well over one million people in PA with hearing losses apparently do little or nothing to help themselves hear better.

While I was still living in Canada, I heard that about 6 out of 7 hard-of-hearing people either deny they have a hearing loss or do nothing about it. Apparently the figures in PA are not much better. It appears that roughly 80% of the hard-of-hearing population in PA is ignoring their hearing problems.

Many of these people do not know where to go for help. We need to make them aware that SHHH is the national voice for hard-of-hearing people and that we are out there working on their behalf.

Are you as shocked as I am that out of 1.3 million hard-of-hearing people in PA, only about 650 belong to SHHH? We need to do something about this.

I was recently talking with a fellow from Finland. He mentioned that the Finnish Federation of Hard of Hearing People (the Finnish equivalent of SHHH) has 16,000 members. This also shocked me.

PA has a population 2.4 times greater than the whole of Finland. If we had a membership comparable to the FFHOH, we would have more than 38,000 SHHH members in PA instead of the 650 we have today!

If other countries can do it, so can we! Let's not keep SHHH the best kept secret in town. The recent Employment Conference reported elsewhere in this issue was a step in the right direction. Let's keep the momentum going. Together we can do it. I'd love to hear what you are doing to spread the word. I look forward to your email.

Neil Bauman, Editor
editor@pa-shhh.org

Employment Conference Rated "Excellent"

by *Diana Bender*

The first PA-SHHH employment conference was held April 4, 2003 at the Radisson Hotel Valley Forge in King of Prussia, PA with 143 people in attendance. Hard of hearing professionals with the support of the Pennsylvania Office of Vocational Rehabilitation (OVR) and Team PA CareerLink developed this regional one-day conference. Attendees included hard-of-hearing employees, students and job seekers, as well as employers and vocational rehabilitation counselors. Counselors earned five continuing education credits for their attendance.

Marcia Finisdore, PA-SHHH State Director, opened the conference by discussing the impact of hearing loss on work and life. Other speakers then addressed a variety of issues of concern to hard-of-hearing people in the workforce. Thomas Boyle, District Administrator of the Office of Vocational Rehabilitation, discussed the help OVR provides to hard-of-hearing employees to obtain and keep a job. Al Lewandowski and Deborah Wallace, from Team PA CareerLink explained unemployment compensation procedures and job assistance programs. Janet Fiore, CEO of the Sierra Group, explained how a hard-of-hearing employee can draw up a personal plan of achievement to get and keep a job. Margaret McKenna, a staff attorney from the Center for Disability Law and Policy, discussed legal issues related to hearing loss and the Americans with Disabilities

Act (ADA). Diana Bender, PA-SHHH Secretary, discussed how to identify and obtain needed assistive equipment while on the job.



As judged by the feedback provided by attendees, the conference was very successful. Attendees stated that all of the speakers did an excellent job. The interaction between Vocational Rehabilitation Counselors, their customers, and employers was positive. The captioning, assistive listening devices, and interpreters made the conference communication accessible. An additional benefit was the learning experience for people who had no experience with various forms of communication access before this conference.

(Continued on page 4)

Full or Half Day Workshops

available through PA-SHHH include:

- **Employment**
- **Coping Strategies**
- **Public Policy**
- **Accessibility/ADA**
- **Speechreading**
- **Hearing Loss 101**

Contact: Marcia Finisdore (finisdore@pa-shhh.org) or,
 Diana Bender (bender@pa-shhh.org)

“Working Together” Conference Really Worked

by *Neil Bauman*

The recent Employment Conference for hard-of-hearing people in Valley Forge, PA was “extremely successful, beyond our expectations” according to Diana Bender, one of the conference organizers. These and similar sentiments were echoed by not only the attendees, but also by the presenters and the exhibitors.

According to presenter, Janet Fiore of The Sierra Group, the conference was “filled with energy and enthusiasm” along with “lots of information exchange.”

Attendees walked away with heads full of ideas they could put into practice in their lives and fists full of literature from handouts at the sessions and brochures from the vendors. One attendee declared, “I thought this was just going to be a group of hard-of-hearing people sharing their ideas.” Boy was he surprised! After the conference he commented, “Now I know a lot more about the services available to hard-of-hearing people and how to access them.”

“The entire conference was excellent. The network of speakers was varied to touch on every aspect of a hard-of-hearing persons’ needs in the workplace.”

There was something for everyone. Some wanted (and received) “information on technology.” Others were amazed at the “wide range of information available” to help hard-of-hearing people cope in the working world. For others it was “being around people with similar problems” and

“learning from hearing-impaired people themselves.”

When attendees exclaim about the “passion and knowledge of presenters for hard-of-hearing people” you know the conference is a success.

Many were impressed in seeing real time captioning (CART—Communication Access Realtime Translation) for the first time and realizing its numerous possibilities in the workplace to make the lives of hard-of-hearing people easier and more productive.

The panel discussion really opened people’s eyes to “the variety of experiences and span of accommodation needs” that could be met. You get “different perspectives from different people.” You learned how hard-of-hearing people “are affected on the job.”

However, just learning ways to accommodate a hard-of-hearing person’s needs is one thing. Putting what you learn into practice is another thing. Attendees determined to go out and do just that. As one attendee declared, “After this conference, I will advocate for myself.” Another determined to work at “being more assertive” and find out “what I need in the way of Assistive Listening Devices and special phones.” Yet another determined to “use the resources discovered.”

Nor was it all one-sided. Hearing attendees also caught the vision. As one reported, “I now know how to deal with my hearing impaired friends, customers and co-workers.” An employer said, “I will look at our office and see what changes we should consider.” One parent saw where she could “help my daughter be a better advocate for herself.”

These good resolutions have not all fallen by the wayside. One of the presenters, Margaret McKenna, an attorney with the Center for Disability Law

Deadline for Submissions

We are always interested in receiving any news, articles or information of interest to hard-of-hearing people in PA. The deadline for submissions for the September issue of *HearSay* is July 15, 2003. Email your submissions to either:

- Neil Bauman, Editor (editor@pa-shhh.org) or,
- Gerry Rusher, Assistant Editor (rusher@pa-shhh.org) or,
- Mail them to Neil Bauman, *HearSay* Editor, 49 Piston Court, Stewartstown, PA 17363.

and Policy recently wrote; “I have already received some follow up calls from participants who can benefit from our services.”

Margaret further declared, “Working together we can all produce positive change.” Tom Boyle, District Administrator of the Office of Vocational Rehabilitation (OVR) echoed these sentiments. He stated, “As a presenter, I was impressed with the number of individuals who attended the conference and with their desire to learn as much as possible about employment related issues.... I believe the Conference succeeded in its basic goal of ‘Working Together’. It clearly demonstrated that employers and people with hearing loss can only succeed when they work together!”

The tragedy today in Pennsylvania is that many hard-of-hearing people still aren’t even aware that there are programs and technology backed by knowledgeable people ready and willing to help them live successful lives both in the workplace and in society. As a result, we need more such conferences.

What makes this kind of conference so worthwhile is summed up in the poignant words of one hard-of-hearing attendee who stated, “Today I learned I could get help.”

Bulk Copies of *HearSay* for Distribution

In the future, if you would like to receive bulk copies of *HearSay* to distribute in hospitals, audiologists offices, seniors homes, etc., please email Alice (pakhtigian@pa-shhh.org) by July 15 and let her know how many copies of the September issue you could profitably use.

Sprint to Sponsor Leadership Training Conference in Pennsylvania

by *Diana Bender*

Sprint will sponsor a 1½ day leadership training conference at the Holiday Inn in Grantville, PA (just NE of Harrisburg) on September 12 and 13, 2003. This conference will begin Friday afternoon and continue all day Saturday.

The conference is intended for people who are interested in furthering the goals of PA-SHHH in Pennsylvania. PA-SHHH is working to improve the lives of people living with a hearing loss by advocating for accessibility and educating people about available technology that improves their ability to understand speech.

Conference participants will learn how to involve themselves in outreach for the Telecommunications Relay Service (TRS), the telephone service that enables people with severe hearing losses to use the phone. In addition, they will learn how to advocate for the needs of hard-of-hearing people in the Commonwealth. Finally, they will learn how to work with various state agencies and how to effectively serve on their advisory boards.

Employment Conference

(Continued from page 2)

The exhibitors received rave reviews in the evaluations. Exhibitors included OVR, Team PA CareerLink, Potomac Technology, Audex, PA Relay Service, Institute on Disabilities, Center on Hearing and Deafness, Philadelphia Brokerage, Liberty Resources, Advanced Bionics, Cochlear Americas, Med El Corporation, Center for Community and Professional

Anyone who serves on a state advisory board has the ability to directly influence the lives of hard of hearing people in PA. For example, the current CapTel trial, the ongoing trial of a new telephone that provides real-time captioning for telephone calls, resulted from actions taken by the TRS Advisory Board. Currently 2 SHHH members serve on this board. Serving as a member of a state advisory board is a rewarding and fulfilling experience.

This conference is free to you if you are accepted. PA-SHHH will pay for your hotel accommodations, meals and travel expenses.

In order that you will be able to “hear” and actively participate in all workshops and sessions, PA-SHHH will provide assistive listening devices (ALDs) and real time captioning (CART).

If you want more information about this conference, or to apply to attend this Leadership Training Conference, please contact Diana Bender at bender@pa-shhh.org or write to her at 101 Oakwood Lane, Phoenixville, PA 19460.

Services and SHHH. Conference attendees appreciated the opportunity to learn about services available and new technology. Many assistive devices were available for closer examination.

The Montgomery County Workforce Investment Board and the Boeing Company provided generous financial support for the conference. Assistive listening devices, real-time captioning, and interpreters were made possible by Audex, the State Independent Living Council, the OVR Bureau of Central Operations, and the PA Office for the Deaf and Hard of Hearing. Independence Press, Inc. donated printing of the conference brochures.

PA-SHHH plans to sponsor additional conferences in other regions of PA in the future.

Why Not CART, ALDs?

When our new Governor was sworn in, sign language interpreters were provided for all events. There was not a single request for an interpreter nor were there any deaf people in attendance at these events. Interpreters were provided “to make the event accessible to the deaf and hard of hearing.”

Unfortunately, the Department of General Services has been led to believe (from agencies that are supposed to be working for the deaf **and** hard of hearing) that simply providing interpreters makes an event accessible to people with impaired hearing.

I wonder how many people would have benefitted if assistive listening devices (ALDs) and real time captioning (CART) had been provided instead.

New SHHH Chapter Coming to Hanover?

There appears to be considerable interest in starting a new SHHH chapter in Hanover according to Neil Bauman and Charles Davis. The results of two recent exploratory meetings were very favorable.

On April 29, 18 people came to an informational meeting at the Homewood at Plum Creek seniors home. Another 36 people turned up for a similar meeting on May 5 at the Brethren Home.

Both meetings had lively question periods as attendees jumped at the chance to get their pressing questions answered.

“There is obviously a real need in this area,” said Bauman, “as people came from as far away as York in the east and Gettysburg in the west.”

Away? Let Us Know

With each issue of *HearSay*, a number of copies are returned because people are temporarily away. Please let Alice (pakhtigian@pa-shhh.org) know if you are going to be away for an extended period. This will save us a bundle in postage. Thanks.

Mission of HearSay

The mission of *HearSay* is to educate and inform people about activities and issues concerning hearing loss in Pennsylvania.

Remote CART—My Experience

by *Marianne Lock*

Returning to graduate school when you have a severe to profound hearing loss like I do can be scary. It is even more unnerving since my hearing has dropped considerably since I graduated from college 15 years ago. The good news is that there are more accommodations for hard-of-hearing people today than there were 15 years ago.

In my first graduate school class, I tried both an FM system and an infrared system. Neither system worked well for me in the classroom because I have poor discrimination—that is—I cannot always understand what I hear, even when the sounds are loud enough.

Thus with these systems, I still also need the instructor to speak slowly, clearly, and face me at all times so that I can speechread. This simply does not happen in the classroom. The professor writes on the blackboard while speaking. He paces around the room. Furthermore, the students are scattered around the room—some quite a distance from me. (I sit up front, of course.)

What I really needed was some visual means of “hearing” the instructor and students. After some negotiating, my university finally consented to get me real time captioning (CART). CART is a godsend to me. For the first time, I am able to “hear” everything that is said in the classroom.

The downside of CART is that it is quite expensive—especially to have the captioner present in the classroom. Therefore, I agreed to try a new technological development called remote CART. With remote CART, the captioner

does not have to be present. In fact, the captioner may be anywhere in the country since she is linked to me via the Internet. In my area, Archive Reporting Service of Harrisburg, (www.archive-reporting.com) provides this service.

For remote CART to work, you need a Pentium II, 500 MHz or faster computer with at least 128 MB of free hard drive space, 100 MHz or faster memory, a SoundBlaster compatible sound card, a microphone, Windows 98 or higher, special remote CART software (which is free) and an Internet connection.

“For the first time, I am able to ‘hear’ everything that is said in the classroom.”

Here’s how remote CART works. The teacher or presenter speaks into a microphone that is attached to my computer. My computer sends their voice over the Internet to wherever the remote captioner is. The captioner transcribes the words in real time and sends them back over the Internet to my computer where I read the words on my computer screen only seconds later.

One of the neat features of remote CART is that in addition to instantly being able to see what is being spoken, I can save, print, or review all the classroom dialogue at my leisure. Furthermore, remote CART is much less conspicuous than when I have a captioner sitting beside me, typing away.

To use remote CART, when I enter the classroom all I do is turn on my computer and log into the remote captioning site where my captioner greets me. (Of course, I have previously arranged my captioning schedule with her.) She listens to whatever is said in the classroom and captions it for me to read.

For Rent

Hard of hearing accessibility needs for meetings—large or small. Assistive Listening Devices available include:

- FM systems
- Infrared systems
- Audio-induction loops

Contact Walt Jensen:
jensen@pa-shhh.org.

The professor uses one microphone. In addition, a larger microphone that sits on his desk is pointed towards the students so the remote captioner can also hear what they are saying.

So far, the only problem I have encountered is when several students try to speak at the same time. When this happens, the captioner can’t make out what anyone is saying (naturally). However, for the most part, remote CART works great! If you are hard of hearing and have classes or attend meetings, I highly recommend CART or remote CART.

Marianne Lock is the PA-SHHH Treasurer and a PA-SHHH State Coordinator. She is a CPA and is currently working towards her Master’s Degree in Taxation. You can reach her at lock@pa-shhh.org.

Support SHHH

One way you can make a difference to hard-of-hearing people is to remember SHHH in your will. That way your money will continue to help hard-of-hearing people long after you are gone.

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HearSay Subscription

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

Name: _____ Phone: _____

Address: _____

City: _____ State: _____ Zip: _____

E-mail: _____

- Enclosed is my contribution of \$ _____ to support *HearSay*. Donations are tax deductible and will be acknowledged in the newsletter and on the website.
- If you wish to remain anonymous, please check here.
- I cannot contribute, but I would like to receive the *HearSay*.

Make donations payable to PA-SHHH and send this form to

Marcia Finisdore, State Director, PA-SHHH
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PA-SHHH is a totally volunteer organization. We rely upon the generosity of our supporters. Each issue of *HearSay* costs just under \$1,000 to produce and mail.

A special thanks to those of you who help make it possible.

James Burke, Morris Henken, Hazel Kriner, Mary Ellen Ladley, Carolyn Meyer, Kevin O'Rourke, Dr. Irwin Rothman, Jim Staszewski, Elam Zimmerman

We apologize if we have missed someone. Please contact Marcia Finisdore for such corrections.

About SHHH

Self Help for Hard of Hearing People, Inc., founded in 1979, is a non-profit consumer self-help organization. SHHH opens the world of communication to people with hearing loss by providing information, education, support and advocacy.

The primary purpose of all SHHH members is to educate ourselves, our families, friends, co-workers, teachers, hearing health care providers, industry, government, and others about hearing loss.

SHHH has members and chapters in all 50 states. To find the chapter closest to you, contact a member of the PA-SHHH state committee if you are in PA, or contact the SHHH National Office.

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PA-SHHH Needs You



SHHH volunteers from all over the Commonwealth assist the PA-SHHH State Director by serving on the PA-SHHH Advisory Council or one of its committees. The PA-SHHH Advisory Council meets periodically in Carlisle. Committees conduct most of their business by email but meet periodically in various parts of the state as needed. We would be delighted to have you join us. If you would like to serve on either the Advisory Council, or one of its committees, please contact the State Director or the appropriate committee chairperson listed below.

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"Come and join us. You will be welcome!"