

HEARSAY

Volume 2, No. 1 March 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

As I write this Pennsylvania is in a deep freeze with snow on the ground in many areas. The good news is the drought is over in most parts of the state. Plant and seed catalogs fill the mailbox bringing hope for a glorious spring.

This issue of *HearSay* brings you good news and hope for hard of hearing people as well! An employment conference in Southeastern PA is scheduled in April with the financial support of the Montgomery County Workforce Investment Board and the cooperative efforts of OVR and Career Links. Soon to appear in your mailbox will be an application for another Train the Trainer Program organized by the PA Office of Mental Health and Substance Abuse Services in May. In this issue, you can read the exciting news of the Universal Newborn Infant Screening effort in PA. Watch for more information about a Leadership Training in the fall. Check the PA-SHHH website (www.pa-shhh.org) for updates on all of these issues and events.

Join us in helping PA-SHHH make hearing loss an issue of concern to all people in Pennsylvania.

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

Each year brings change. This year is no different. The founding editor of *HearSay*, Maggie Casteel, decided it was time for her to move on. Thanks Maggie for your hard work in starting and producing this award-winning newsletter!

I (Neil Bauman) am your new editor/publisher and look forward to continuing the same tradition of excellence with this newsletter. In case you are wondering, yes, I too, am hard-of-hearing. In fact, I was born with a severe hearing loss so I well know the communication challenges we hard-of-hearing people face daily. For those of you who don't know me, I am a speaker and author on hearing loss issues. (If you are interested in what I do, or to learn more about hearing loss, check out my website at www.hearinglosshelp.com.)

Beginning with this issue, *HearSay* will also be available from our PA-SHHH website. The link to read the electronic version is www.pa-shhh.org/Hearsay.pdf. The on-line newsletter is in PDF format (so it looks identical to this paper version). You will need the free Adobe Acrobat Reader to read it. Downloading is fast, ranging from about 10 seconds for 28.8 KB modems to almost instantaneous for those with high speed/broadband connections.

If you only want to receive the on-line version instead of the paper copy (and save PA-SHHH some money in the process), email your request to Alice at pakhtigian@pa-shhh.org. As each new issue is published, you will receive an email giving you the link to the current newsletter.

As always, I am interested in your ideas and articles for this newsletter. Send them to me or to Gerry Rusher (gerlhoh@snip.net), the assistant editor of *HearSay*.

Neil Bauman, Editor
editor@pa-shhh.org

"Working Together"

A One Day Employment Conference for Employers and Hard of Hearing Employees

The first PA-SHHH employment conference will be held at the Radisson Valley Forge in King of Prussia, PA on Friday, April 4, 2003. "WORKING TOGETHER" is a one-day conference for employers and employees or job seekers who are hard of hearing. The conference is sponsored by the Pennsylvania State Office of SHHH, with the financial support of the Montgomery County Workforce Investment Board.

The conference has been developed by hard of hearing professionals with the support of the Pennsylvania Office of Vocational Rehabilitation (OVR) and Team PA CareerLink. Workshops will cover a broad range of topics including: assistive technology, hearing aids, coping and communication strategies, legal rights of employee and employers, and dealing with hearing loss on the job and when seeking a job. Workshop presenters include Thomas Boyle, OVR District Administrator; Deborah Wallace, Workforce Development Representative, Philadelphia, Unemployment Compensation Service Center; Margaret McKenna, Staff Attorney, Center for Disability Law and Policy; and Janet D. Fiore, CEO, The Sierra Group, Inc. Exhibits of assistive devices and other information will be available. Assistive listening systems, CART (real-time captioning) and ASL interpreters will be provided for all sessions. An application for Continuing Education Credits has been submitted.

This conference is intended for:

- Employers
- Human Resources Personnel
- Hard of Hearing Employees
- Hard of Hearing Job Seekers
- Hard of Hearing Students planning to enter the workforce

The cost for registration is \$35 per person or \$60 for a student with accompanying parent. Limited registration after March 21, 2003 or on-site will cost \$40 per person. The registration fee includes continental breakfast, lunch and attendance at all workshops, sessions and the exhibit hall. For those of you who live too far away to participate, PA-SHHH plans to repeat this conference in western Pennsylvania at a later date.

You can obtain additional information, together with directions to the hotel and the preliminary program from the PA-SHHH website at www.pa-shhh.org. If you have any questions, contact Ronnie Adler by telephone or mail. See the bottom of the Registration Form on page 5 for her contact information.

If you would like to attend, please complete the registration form (page 5) and return it by March 21, 2003. On-site registrations will be limited. We may not be able to accommodate those who do not register by March 21.



Pennsylvania's Newborn Hearing Screening Program

by *Karl Hoffman*, Program Administrator,
PA Newborn Infant Screening

Technological advances have made it possible to detect hearing impairment at birth. Studies estimate that approximately 3 of every 1,000 infants are born with impaired hearing, making it the most prevalent of all birth defects. If undetected by parents or caregivers, hearing impairment can adversely affect development as the child struggles to communicate, build vocabulary, and develop language skills.

Early detection, treatment, and intervention with appropriate family supports can help children overcome impediments to acquiring speech and language, thus improving their outlook for social, emotional, and cognitive development. Technological intervention such as digital hearing aids and cochlear implants, the selection of a communication method/language such as American Sign Language, and other family and instructional program supports can help to keep the hearing-impaired child on a par with his or her peers.

Because Universal Newborn Hearing Screening and Intervention (UNHSI) was rapidly emerging as a standard in newborn care, the Pennsylvania Department of Health (DOH) received funding from the General Assembly in 1999 to begin a newborn hearing screening pilot project in 26 of the state's estimated 140 birthing hospitals. Participating hospitals received funds to purchase screening equipment and for staff training. The hospitals agreed to provide *universal* hearing screening to all newborns, as opposed to just those identified as being at risk.

The results of this 3-year project provided the groundwork needed to begin the program statewide. Corresponding legislation, known as the Infant Hearing Education, Assessment, Reporting and Referral (IHEARR) Act (Act 89 of 2001), passed the General Assembly, and was enacted on November 30, 2001, requiring

DOH to develop and administer a statewide comprehensive newborn hearing screening and follow-up program.

The objective of this law is to identify newborns with hearing impairment as soon as possible through early screening and diagnosis, and to assure their linkage to appropriate treatment and services. Hospitals submit patient data to DOH to ensure that newborns are screened within 30 days, diagnosed within three months, and referred for treatment and intervention before the age of six months. Hospitals also inform parents about the importance of newborn hearing screening and early intervention as it relates to the baby's development. Statewide implementation began on July 1, 2002.

With the implementation of Act 89, newborn hearing screening has indeed become a standard of newborn infant care in Pennsylvania. In the spring of 2002, the Infant Hearing Screening Advisory Committee, consisting of two neonatologists, two audiologists, and two advocates, was appointed by the Secretary of Health to provide recommendations and technical assistance to guide the program. An additional 68 birthing hospitals received \$10,000 mini-grants for program startup. Guidelines to steer the program through its first year were developed and were distributed to all birthing hospitals. An informational 'rack card' was developed and was sent to all birthing hospitals for mass distribution to new and expecting parents.

To launch the statewide effort, a 3-day conference was held in State College in June of 2002. More than 150 hospital screeners and other professionals attended. Advisory committee members, DOH staff, and national program experts made presentations. Subcommittees have since contributed additional expertise by recommending changes in follow-up, audiology, training, and outreach, and by

using information technology. In recognition of this statewide initiative, DOH received a 4-year UNHSI grant of \$250,000 per year from the Health Resources and Services Administration of the U.S. Department of Health and Human Services to further strengthen and increase the scope of the program.

Hospitals submit data to DOH monthly on the number of births, the number of infants screened, and the results of screenings. Hospitals also report on individual infants who did not pass the screening prior to discharge so that a DOH nurse consultant can track and follow-up on these children.

Administrative activities include collecting and analyzing monthly data to ensure that hospitals are performing the screenings, reviewing individual patient data, and contacting primary care providers and parents when a newborn does not pass the screening. This assures the child receives diagnostic evaluation, treatment and services. DOH also provides the money and resources for continued development of outreach materials, training, and application of technology.

During the coming year, DOH will present six regional one-day workshops to train hospital screening staff and other professionals. Also, it will work with the Pennsylvania Chapter of the American Academy of Pediatrics to develop specialized outreach training for physicians. DOH has engaged the services of a consultant to gather system requirements as a prelude to launching a web-based data collection and tracking system to conduct follow-up activities more effectively.

DOH's goal is to achieve 85% screening of all newborns by June 30, 2003—and beyond that—to further improve this percentage until 100% of

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Advocating for Access

by *Diana Bender*

SHHH members who attend local chapter meetings are well acquainted with the advantages of assistive listening devices (ALDs) in providing increased comprehension of the spoken word during the meeting. ALDs are also used in many theaters and auditoriums, and enable many of us who live with a hearing loss to enjoy these programs. These accommodations are required in all public places, thanks to the Americans with Disabilities Act (ADA). Private organizations are not covered under the ADA and are therefore not required to install ALDs. However, most of them would like to accommodate us, if financially feasible, provided they know there is a need for them.

In October 2002 two members of Montco Chapter, President Rod Ryan and Diana Bender, met with representatives of the Archdiocese of Philadelphia to request that ALDs be installed in all Catholic churches in the Philadelphia region. Sister Kathleen Schipani and Lori Brew of the Department for Pastoral Care for Persons with Disabilities of the

Archdiocese of Philadelphia explained that their department provides assistance for any Catholic church in the diocese that would like to install ALDs. This assistance includes providing information on ALDs, loaning equipment to a church so that parishioners can try it, and locating suppliers of ALDs. ALDs may be installed both in the church itself and/or in the confessional.

The Archdiocese does not require that all churches have ALDs, but rather serves as a resource for churches that want to install them. Although Sister Kathleen's department has informed all the churches it serves that they can help with ALDs, it is important to remember that the individual church must initiate the process of obtaining an ALD by contacting her department.

The most important thing we learned at this meeting is that in the Archdiocese of Philadelphia, you must ask for access if

your church does not already have an ALD. This is also likely the case in other regions of Pennsylvania and for other religious institutions as well. Remember that few people with normal hearing have any idea of what an ALD is and how it can benefit a person with hearing loss. Presumably, most religious organizations have resources similar to those provided by the Catholic Archdiocese in Philadelphia. Therefore, individual churches and synagogues can find out how to provide accommodations that will enable you to participate in religious services.

Information on ALDs is also available through the SHHH website at www.shhh.org. Since hearing loss increases dramatically with age and since a higher proportion of older people attend religious services, there are likely many other members who would benefit from the ALDs you request.

Office for the Deaf and Hard of Hearing (ODHH)

by *Teresa Nellans*, ODHH Liason to PA SHHH State Office

The Pennsylvania Office for the Deaf and Hard of Hearing (ODHH) looks back on the year 2002 with pride in its accomplishments for advocacy of individuals with hearing loss or deafness.

ODHH recently provided accommodations at the 'Workshop On Hearing Loss' in Erie. Teresa Nellans gave powerpoint presentations regarding hearing loss to several Team Pennsylvania Career Link Centers in western Pennsylvania, as well as other organizations.

Advocacy by ODHH staff was provided in the areas of health, mental health, interpreting, dental, community living, financing, employment, hearing dogs, hearing aids and assistive listening systems, real time captioning, housing, jail, and legal matters.

ODHH staff include: Denise Brown (denibrown@state.pa.us), Allentown, Lehigh County; Dee Dee Schenk

(dschenk@state.pa.us), Harrisburg, Dauphin County; Teresa Nellans (tnellans@state.pa.us), Johnstown, Cambria County; and Gerald Penna (gpenna@state.pa.us), Erie, Erie County.

Please visit the PA PowerPort at www.state.pa.us, PA Keyword: Disability Services. Here you will find various programs and services associated with the Pennsylvania Department of Labor and Industry's Office of Vocational Rehabilitation (OVR). You can also click on the ODHH 'Interpreter Database' and receive names of certified interpreters in each county of Pennsylvania. To get the complete list of interpreters (not only emergency) you need to select "all."

In 2003, ODHH has some exciting happenings! You are encouraged to attend the following public meetings. Since times and locations are yet to be determined, please call, toll-free, the ODHH central office at 1-800-233-3008 (or

Newborn Screening

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newborns are screened. Preliminary analysis indicates that the initial 85% screening goal has already been achieved. Improving on this performance and ensuring that each child diagnosed with hearing impairment is linked to comprehensive early intervention services will require a sustained effort. To this end, DOH will continue to work with its advisory committee, healthcare professionals and advocacy groups to further improve the network of available services.

For more information about the Newborn Hearing Screening Program, contact Karl Hoffman, Program Administrator, at (717) 783-8143 or by email at nbhs@state.pa.us.

(Continued on page 5)

“Working Together” Registration Form

Name _____

Address _____

Phone _____ Home __ Work __ TTY __ V __

Email _____

Accessibility Needs:

Assistive listening systems, real-time captioning (CART) and ASL interpreters will be provided for all sessions. The hotel is fully accessible to those using wheelchairs. If you require any additional accommodations, please specify:

Fee Schedule:

Student with parent: \$60 for both
Individual, before Mar. 21: \$35
Individual, after March 21 or on-site: \$40

Registration Deadline: March 21, 2003

No refunds for cancellation after March 28
Registration fee includes continental breakfast,
lunch and attendance at all workshops, sessions and exhibit hall

Payment information:

Make check payable to PA-SHHH and send together with this form to:

Ms. Ronnie Adler
649 S. Henderson Road - Apt C-201
King of Prussia, PA 19406
Tel.: 610-354-9392 TTY or 610-265-1432 Voice
Email: adler@pa-shhh.org

ODHH (Continued from page 4)

dschenk@state.pa.us) for more information. Voice and TTY are available at this number.

- Pennsylvania Rehabilitation Council (February 12, April 19, June 11, August 13, October 1 and December 10).
- Office of Mental Health and Substance Abuse Services’ annual ‘Train the Trainer’ (May 8-10).
- Advisory Council for the Deaf and Hard of Hearing (February 7, April 25, September 19 and November 14).
- State Independent Living Council (January 22-23, April 10-11, July 9-10 and October 15-16).
- Training Sessions for Mental Health & Substance Abuse Services Professionals (May 22 and June 4).
- State Board of Vocational Rehabilitation (March 11, June 3, September 16 and December 2).
- Advisory Committee for Persons who are Deaf and Hard of Hearing (March 28, June 6, September 12 and December 5).
- Pennsylvania Protection and Advocacy (March 7, June 6, September 12 and December 5).

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
8 Azalea Lane,
Media, Pa 19063-2240



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.

Rosalie Carnese, Rosaria Crimaldi, Linda Dallas, Maurice Feldman, Anna Herr, Maryellen Ladley, Alberta McAviney, Anna Miller, Tammy Rattigan, Dr. Irwin Rothman, 4 Anonymous

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.

Selp-Help for Hard of Hearing People
7910 Woodmont Avenue, Suite 1200
Bethesda, MD 20814

Phone: (301) 657-2248 (Voice)
(301) 657-2249 (TTY)
(301) 913-9413 (FAX)

Email: info@shhh.org
Website: www.shhh.org

PA-SHHH Committees



The PA-SHHH Office is served by volunteer Committee members from all over the Commonwealth. This Committee meets periodically in various parts of the state, but attendance is not mandatory. We welcome and encourage your interest and participation in the PA-SHHH office. If you would like to know more about any of the PA-SHHH Committees, or would like to become a Committee member, please contact the Chairperson listed.

State Director: **Marcia Finisdore** finisdore@pa-shhh.org

Membership: **Ronnie Adler** adler@pa-shhh.org
Marianne Lock lock@pa-shhh.org

Communication: **Neil Bauman** bauman@pa-shhh.org
Alice Pakhtigian pakhtigian@pa-shhh.org

Government Affairs: **Diana Bender** bender@pa-shhh.org

Development: **Bill Pfeifer** pfeifer@pa-shhh.org

“Come and join us. You will be welcome!”