



# The Official Newsletter of HLAA-PA

Support and Advocacy since 2001 for Pennsylvanians with Hearing Loss

Link to text-only Issue 4 Winter 2020 hlaa-pa.org/HearSayArchive/HearSay20204text.pdf

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### **HearSay Articles**

HLAA-PA welcomes articles of interest to the hearing loss community for publication in HearSay, as well as suggestions for topics. Send e-mail to editor@hlaa-pa.org

#### **DISCLAIMER**

Opinions expressed in HearSay are those of the authors. Mention of goods and services in articles and advertisements does not mean HLAA-PA endorsement, nor does absence suggest disapproval.

To reach readers of HearSay, contact Lee Williams

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# Nancy's Message by Nancy Kingsley, *State Director*

You probably know that as of July 1, face masks must be worn in public locations in Pennsylvania in order to reduce the spread of COVID-19. This requirement applies to outdoor locations when a distance of six feet can't be consistently maintained, as well as to indoor public locations; public transportation, healthcare settings, and at work. There are some exceptions to the mask requirement, and an important one applies to us. It covers "individuals who are communicating or seeking to communicate with someone who is hearingimpaired or has another disability, where the ability to see the mouth is essential for communication." The order also states that people are not required to show documentation that an exception applies. You can read, copy, and/or download the order <a href="here">here</a>:

The parts applying to communication access are in Section 3

We are fortunate that the need for a face mask communication exception has been recognized, and we shouldn't hesitate to inform others about it when we need them to lower or remove their mask so we can see their lips. If necessary, we can explain that this exception is permitted by Pennsylvania's mask requirement. I had to cite this exception at a grocery store where the checkout clerk refused to lower her mask while speaking to me. If you need assistance in getting compliance, contact the Office for the Deaf and Hard of Hearing (ODHH) at 717-783-4912. (Face masks with a clear panel over the mouth have been developed to enable speechreading, but they are in short supply.)

Hopefully, a vaccine and/or effective treatment for COVID-19 will be available in the near future to eliminate the need for masks, but until that time arrives, we can still ensure that effective communication will provided to us.

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## **State Happenings**

# by Carolyn Meyer, Outreach Coordinator

As we commend the "Heroes" of the medical profession who have served so valiantly in the past months, we pause to reflect on the work of our own "HLAA Heroes" who are working to further the mission of our organization. To all the chapter leaders, state coordinators, state officers, Walk 4 Hearing volunteers, HearSay and website staff--you have provided us with the strength to move forward. With chapter meetings currently not a possibility, you have created new boundaries for us. With platforms like Zoom and Google Meet, you have worked to provide our members and friends with hearing loss a framework for continuing our goals and providing support to those who need it in all communities of the state. This is no easy task. We know the countless hours you spend trying to orchestrate what will be the best way for us all to communicate as well as we possibly can with our hearing loss. We thank you for your dedication.

## **CHAPTERS**

In recent weeks, both the MontCo and ChesCo chapters have invited members and visitors to join their meetings. MontCo has been using Zoom for several meetings. It works well. ChesCo now had its first meeting using Google Meet. With Google Meet the captions can be displayed on the bottom of the screen and seem to work well. Many

participants liked the free caption feature whereas with Zoom captions are an additional cost. However, if you have a smart phone, that can help you to caption the meeting. The app to use with iPhones is Otter and for Android phones use Google Live Transcribe. Both are available from your App Store. Position your phone so it is close enough to the microphone on your computer or iPad and also visible to you as you attend the meetings. These suggestions were presented by members attending the meetings. As with all these platforms, there are details that have to be worked through. Over time we can determine how best to suit our own members. The important goal is to continue our meetings on some regular schedule. At these recent meetings, members had the opportunity to share how they were coping individually with their own hearing loss during the pandemic. Many use Otter and Google Live Transcribe when interacting with medical care professionals and others to facilitate communication. Those who already use InnoCaption should have received an email indicating the company's revision of their website, new features, and new logo. Virtual meetings present an opportunity to continue meeting schedules in the winter months when many of our meetings have been cancelled due to inclement weather.

### **WALK 4 HEARING GOES VIRTUAL**

Sunday October 18, 2020 9:45 registration and the program begins at 10 AM.. You can also register online ahead of time. Make sure to RSVP to Walk Day to take part in the events. Go to the Pennsylvania <a href="Walk4Hearing">Walk4Hearing</a> Online Celebration on <a href="www.walk4hearing.org">www.walk4hearing.org</a> website and fill in your information so you can join the festivities. There will be special guests, chances to win prizes, and an opportunity to share stories. You will receive a response once you RSVP. When the celebration is over, we encourage you to walk safely in your own neighborhoods with friends and family. For Walkers who raise \$100.00 or more, you will receive the special Walk tee shirt in the mail after the event.

### **FARM SHOW 2021**

As you all have probably been informed, the annual event in Harrisburg will be a virtual event. It has never been cancelled in 104 years. In-person events and competitions will not be held. As of now, there may be some semblance of a food court, but virtual events will focus on education and awareness for the general public and agriculture industry. HLAA-PA does not know as of now what its role will be but will inform you in the next issue of HearSay. The Farm Show schedule is January 9-16, 2021

## AN INTERESTING STORY FROM A VOLUNTEER

Over the summer many of our chapter leaders received an email from a 13-year-old student with hearing loss who attends the Downingtown STEM Academy. Yaduraj Choudhary is in 10th grade and wanted to offer his time to help to support and advocate for people with hearing loss. Please read his article in this edition of HearSay to know more about him and see what he is doing as a volunteer.

### **HLAA CONVENTION 2020**

This year's virtual convention, "Experience HLAA", was truly unique. Two days of captioned webinars and presentations are now available in the convention archives at www.hearingloss.org for you to view if you missed it. The first day had 800 attendees

with a total registration overall of 2400 viewers, the majority of whom used desktop PCs or laptops. When you go to the hearing loss website, click on "Convention". Then find "Access Experience HLAA". When you open that, choose a topic that appeals to you. For those suffering from tinnitus, the Research Symposium "The Latest on Tinnitus Research" might be very informative. For me, as your columnist, I particularly enjoyed a presentation on the last day entitled "Hearing Loss and the Health Care System: A Call to Action" by Nicholas Reed, Au.D., Assistant Professor at Johns Hopkins University. Dr Reed, at the conclusion of his presentation, welcomes any emails from viewers who might have questions.

# HLAA CONVENTION JUNE 24-26, 2021 SAN DIEGO , CA

Preliminary details are on the website as to hotel accommodations with more to follow. For questions email convention@hearingloss.org.

# Supporting Healthy Hearing During a Pandemic

It goes without saying that the COVID-19 pandemic has altered the lives and routines of people around the globe. One area (of many) that has had to quickly adapt and create new protocols is the medical field. While frontline workers fight tirelessly to care for those sick and hospitalized, many other medical providers and practices are working overtime to support patients' health needs and provide care in a way that reduces exposure. During times of restricted on-site visits up to now, our audiologists have supported our patients and their hearing device needs.

During a period of limited on-site visits within our hospital system, "curbside" support was offered for the cleaning, troubleshooting, and repair of hearing aids. Now that we are welcoming patients back into our offices, the hospital system is continuing to make every effort to reduce exposure for our patients and staff. The waiting rooms are specifically designed to promote social distancing in addition to extensive disinfection protocols for all areas. Masks continue to be required for all patients and staff who enter our buildings in addition to thermal screenings and oxygen screenings upon entrance to the building and our department. In addition to on-site precautions, virtual services continue to be offered for eligible visits.

Since pandemic-related restrictions began in March, our hospital system has seen a tremendous increase in virtual visits, allowing patients to connect with their doctors and manage their health needs from their own home. Telemedicine is the remote diagnosis and treatment of patients by means of telecommunications technology (such as video calls). Initially seen as a way to serve patients who live long distances from their providers or who are unable to travel safely, telemedicine is becoming more widely used as a means to provide patient care while practicing safe isolation and social distancing.

In the Penn Medicine Hearing & Balance Center, our audiologists are utilizing telemedicine capabilities to offer hearing device support in addition to remote programming of hearing aids. Remote hearing aid programming allows your audiologist to connect your hearing aids to their programming computer in order to make changes to your sound settings. The hearing aids must be connected to a smartphone or tablet using the hearing aid company's app to allow for a virtual session to take place. You may have the option of a live session (like a FaceTime call) with your audiologist or he/she may send changes through the phone app for you to apply. This will depend on your type of hearing aid, the needs to be addressed during the visit, and your audiologist's scheduling availability. It should be noted that remote programming is not

available for all hearing aids or smartphones, nor will all patients benefit from this type of visit. Please consult with your hearing care provider to learn if this is an option for you.

As the world continues to work to handle the COVID-19 pandemic, mask mandates are recommended to reduce viral transmissions. Masks with clear shields allow for speechreading and have been incorporated as needed within our audiology and ENT departments. Our providers have also been working with patients to optimize their hearing aid programming to overcome the challenges of listening to mask-wearing speakers. Masks with ear loops can also create a challenge with the placement and removal of hearing aids. Using increased caution when removing your mask is recommended to avoid loss of a hearing aid. Patients may find it easier to use a mask that ties around the head or an 'ear-saver' that keeps mask loops off the ear.

While the COVID-19 pandemic has disrupted many aspects of daily life, medical practices across the country are finding effective ways to care for their patients' health needs. In our audiology and otolaryngology departments, safety protocols for disinfection, social distancing, and mask guidelines are in place to protect patients and staff. Hearing aid providers are continuing to find ways to support their patients and deal with pandemic-related issues such as wearing hearing aids with masks. The advancements that have been offered during these recent months, such as telemedicine and remote hearing aid programming, will continue to be beneficial even after the pandemic and its related restrictions ease.



Jamie Guinan, AuD, CCC-A Audiologist Penn Medicine Audiology

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# Hearing Loss Association of America-Chester County, PA Chapter Awards 4th Annual College Scholarship

In recognizing the need to encourage post-secondary education among the high school population with hearing loss, our chapter is awarding the 4th Annual Mortimer Bauer Memorial Scholarship Award to Emily Reester of Chester Springs for her award winning essay and a life spent learning how to speak up for herself and advocating for people with hearing loss. In 2018 she co-led a panel with a friend at the Alexander Graham Bell Foundation for the Deaf and Hard of Hearing's National Convention.

Emily is the daughter of Kara & Kevin Reester and is a graduating senior at Downingtown East High School. She will be attending college at the University of the Sciences in Philadelphia, majoring in physical therapy.

# **Emily's Award-winning Essay**

What would you like the world to know about you?

We are born with five senses: sight, touch, hearing, taste, and smell. To everyone around me, I look just like everybody else, but if you look close enough at my ears, I'm not. Day in and day out, I wake up and the first thing I reach for are my hearing aids, sitting on my nightstand. I do

not have normal hearing like everyone else, and this has defined me.

It is no joke: it is not easy being able to hear every day. It took a long time for me to be comfortable with who I am, accept my reality, and embrace it; once I did these things, my hearing loss empowered my every moment. It is something beautiful, something positive and influential, and I want to share this light with the world.

I like to look back and think about the small moments that have shaped me into who I am today. To me, it is the small moments that count like the time I was first able to introduce myself, my disability, and my accommodations comfortably to a teacher; the time I could comfortably respond when kids in school pointed to my ears and asked, "what's that?"; the countless times I asked my friends to speak up so I could hear; and the times I repeatedly asked my dance teachers to wear my Bluetooth microphone, even when they replied no. Moments like these, where I accept and embrace my reality, have strengthened my courage and advocacy.

In the summer of 2018, I proposed a panel to the Alexander Graham Bell Foundation for the Deaf and Hard of Hearing's National Convention, and my proposal was accepted. I collaborated with one of my best friends — who is completely deaf — and we presented our stories about living with hearing loss. As I was sharing my story with strangers — people like parents of hearing-impaired children and hearing loss support teachers — they were eager to listen; they wanted to soak up the significant moments from my life. They asked the types of questions you cannot find answers to in a book, and I was able to talk with and help them to the best of my ability. A mother of a hearing-impaired daughter of my age asked about our methods of advocating for ourselves in the school environment. I told her and the whole audience about how I work to meet my teachers every year prior to the first day of school to introduce myself, my story, and my accommodations. I shared that it was not easy to find the courage to advocate for myself, but I surrounded myself with people who were always kind and encouraging. As we talked, I saw the tense shoulders of mothers of hearing-impaired children lower and the worried creases on their foreheads lessen. I saw light bulbs go off for hearing loss support teachers who gave affirming nods to every response. By the end of our panel, I realized something that I will always keep with me: I was a light of hope for these people, living proof that we have no limitations in life.

Reflecting on the convention later in the year, I remembered the signs of relief in the parents and the support from the teachers. Therein lies the positive influence I set out to achieve; I saw a beautiful change in the outlook of my audience. This was only the beginning of a journey to forever release the light that is my disability. It differentiates me from everyone: it has empowered me, pushed me to find myself, and will continue to propel me to the best version of me.

**Emily Reester** 

# **About Yaduraj**

This summer, several HLAA-PA chapter leaders received an email from Yaduraj Choudhary, a young man with hearing loss who is entering the 10th grade at the Downingtown STEM Academy, although he is only 13 years old. Yaduraj explained that he wanted to become an advocate and supporter for people with hearing loss and volunteer with HLAA in some capacity. I was very impressed by his initiative in finding information about the HLAA chapters and a level of maturity not usually found in someone his age.

Yaduraj's hearing loss was the result of cholesteatoma in both ears. He was born with the condition, but his parents didn't notice his hearing loss until he was 6 years old. A cholesteatoma is a skin growth that occurs in the middle ear behind the eardrum. It is usually due to repeated infections. Cholesteatomas often take the form of a cyst or pouch that sheds layers of old skin that build up inside the ear. Surgery is normally required to remove the excess skin and to

repair any damage to the eardrum. Hearing loss often results. Yaduraj has had 4 surgeries, the first one when he was 6. He now has a prosthetic in his left ear and wears a hearing aid in his right ear. He doesn't use any other assistive listening devices.

Yaduraj has worked hard to live a normal teenage life despite his hearing loss. On the academic front, he has obviously been successful, as he will be entering 10th grade in an academically challenging high school at an age when he would normally be in 7th or 8th grade. He became interested in learning about the COVID-19 virus and how it spreads, and during the summer, he created a three-minute YouTube video explaining virus reproduction numbers, which he presented at the **Breakthrough Junior Challenge.** 

When Yaduraj initially created the video, there were no captions. When told that if he wanted to present to hard of hearing individuals in the future, he needed to learn how to caption presentations. A week later, he submitted the video with captions, which can be seen at the link below.

Yaduraj will be getting involved with the PA Walk4Hearing in October and also wants to work with his school district to spread the word about hearing loss to others. We are looking forward to having him in the HLAA family, and hopefully he will motivate other young persons with hearing loss to get involved as well.

Breakthrough Junior Challenge 2020

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## PA Walk4Hearing Goes Virtual!

On October 18, 2020, the PA Walk4Hearing will celebrate 15 years of raising awareness and uniting people with hearing loss. The Walk4Hearing is a wonderful celebration and centerpiece of our community that provides essential resources and support for people with hearing loss.

We are not letting the COVID-19 pandemic slow us down as we embark on our first Virtual PA Walk4Hearing in 2020. Non-profit organizations like HLAA are struggling due to the pandemic and its effect on people's discretionary income. HLAA depends on the money raised by the Walks to help it to continue to advocate for and educate people with hearing loss. Among its recent activities, HLAA helped to pass the Over-the-Counter (OTC) Hearing Aid Act and is presently working with Congress to enact legislation enabling Medicare to pay for hearing aids.

Besides funding HLAA, money raised from the Walks also supports local non-profits and HLAA chapters; 40% of the amount raised by a team is designated towards the local non-profit organization of that team's choice.

We learned a lot from the virtual HLAA Spring Walks and are planning on holding the largest Walk and raising the most funds of all 20 HLAA Walks in 2020. But we need your help to make the 2020 Virtual PA Walk4Hearing successful. In the past, it was difficult for many people to participate in person. With the Virtual Walk, everyone has a chance to show support for hearing loss advocacy.

So what is a virtual Walk? It an event conducted on the Zoom platform instead of being held in a physical location. Team captains, participants, sponsors, HLAA chapters, and alliance organizations join from their computers at 9:45 am on Sunday, October 18 for an online celebratory and educational experience. To join the online celebration, sign up on the <u>PA Walk website</u> at bit.ly/WalkPA2020.

There will be entertainment and an opportunity to win prizes at our online raffle. Participants are invited to share videos, photos, and stories about why they walk and what they are doing from home to raise funds and awareness. Many teams will then go out for a real walk in their neighborhoods. You will leave the celebration feeling inspired and motivated, so get your family and friends to join the fun. Everyone is welcome, and it's free. For more information about the virtual celebration, contact Ronnie Adler at radler@hearingloss.org

Do I continue to fundraise for a Walk4Hearing event that has a virtual Walk Day? Yes! Your support provides essential resources to people with hearing loss nationally and in local communities where Walks take place. If you participate in the Walk4Hearing through an alliance organization or an HLAA chapter, your support helps that organization receive funding.

This link gives many great tips on how to fundraise for a virtual event.:

If you are not setting up your own team or page, please support our HLAA-PA Advisory Council's team, the HLAA-PA All Stars, at bit.ly/WalkPAAS2020

The HLAA-PA Advisory Council serves all Pennsylvanians with hearing loss, not just the parts of the state with HLAA chapters.

This year, HLAA has teamed up with *American Girl* in honor of the company's 2020 Girl of the Year, Joss Kendrick, a doll with a hearing aid, to increase awareness and educate people about hearing loss. American Girl has donated \$25,000 to support HLAA's educational programs and is collecting donations for HLAA through 2020 at americangirl.com and at stores nationwide.

Children from ages 5-12 who register for the Walk4Hearing can enter the Walk with Joss contest for a chance to win a Joss Kendrick doll and accessory package. Using the button below, they should tell in a short statement or show in an illustration why they want to walk with Joss at the Walk4Hearing. Thanks to *American Girl*, one lucky winner from each Walk4Hearing location will bring Joss home!

If you have any questions about how to participate in or donate to the PA Walk4Hearing, email me at mikemiles\_19087@yahoo.com.

- Mike Miles

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AGRABILITY FOR PENNSYLVANIANS + PA ASSISTIVE TECHNOLOGY FOUNDATION

# HEARING LOSS ON THE FARM

Hearing loss is common among farmers and agricultural workers, but there are ways to prevent and .overcome it.

Hearing loss can occur as part of the aging process, often due to increased exposure to loud, prolonged noise. Noise-induced hearing loss can occur at any age.

Hearing loss does not have to negatively impact your ability to work on the farm and enjoy life.

## When to Consider Hearing Aids

It might be time to consider hearing aids if you experience:

- Difficulty hearing people speak.
- Difficulty hearing high-pitched sounds.
- Turning up the TV or radio to a level higher than comfortable to those around you.
- Ringing or other constant noise in ears.
- Withdrawing from events due to inability to hear.
- Others mentioning potential hearing loss to you.

## **How to Obtain Hearing Aids**

Hearing aids are not *one size fits all* – work with a hearing professional to determine the best technology for your needs.

# The first step is to meet with your primary care physician (PCP).

They can give you a referral to see an audiologist (licensed hearing professional) or otolaryngologist (ear, nose, and throat doctor). This specialist will provide a simple, painless hearing evaluation.

## This evaluation will determine whether you have hearing loss and to what degree.

This specialist can discuss options based on your needs and communication style. If you do not have a PCP, contact a local hearing specialist directly.

# **Farm Factors Impacting Hearing Aids**

Farming factors can impact the selection and use of hearing aids. Rapid changes in noise levels and environmental exposures such as dust and moisture can impact hearing aids. Be sure to discuss these factors with your hearing specialist when selecting hearing aids.

# Wearing Hearing Aids in a Farm Environment:

- Utilize mute functions AND wear hearing protection when working around loud noises such as tractors, saws, and equipment.
- Clean hearing aids regularly daily if working in dirty or dusty conditions.
- Use a drying kit to remove moisture that may occur from perspiration or weather conditions.

Implementing these practices is key to keeping your hearing aids in good working order and to preventing additional hearing loss.

## **Financial Assistance:**

Hearing aids can range in price from under \$1,000 to more than \$8,000. There are funding resources available to help cover this cost. Pennsylvania Assistive Technology Foundation (PATF) is a statewide, nonprofit organization that provides free information and assistance to people with disabilities and older Pennsylvanians to help them fund assistive technology, such as hearing aids. Pennsylvania's Home and Community-Based Services waiver programs also covers hearing aids for those who are eligible. Private health insurance may cover part of the cost of hearing aids.

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# About HLAA and its State Office, HLAA-PA

The Hearing Loss Association of America (HLAA), founded in 1979, is the nation's foremost membership and advocacy organization for people with hearing loss. HLAA opens the world of communication to people with hearing loss by providing information, education, support and advocacy. The national support network includes the Washington, DC area office, 14 state organizations, and 200 local chapters. HLAA is a 501(c)3 non-profit organization.

Hearing Loss Association of America 7910 Woodmont Avenue, Suite 1200 Bethesda, MD 20814 hearingloss.org HLAA-PA is the all-volunteer state office of Hearing Loss Association of America. We were established in 2001 to carry out the mission of HLAA for Pennsylvanians with hearing loss, their families and friends.

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### **VOLUNTEERS NEEDED!!**

Assist the HLAA-PA State Director by serving on the Advisory Council or one of its committees. The Council meets periodically at locations convenient to its membership. 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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Link to online version: tinyurl.com/HearSay20203 20200526