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HLAA-WA 2026 ANNUAL COMMUNITY EVENT MEETING

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CHERI PERAZZOLI: WELCOME, OPENING REMARKS

>>CHERI: Welcome. I am glad to see you to the HLAA-WA community day.
This brings some of the things that we value most. Support, information, and a chance to connect with one another.

I am Cheri Perazzoli and I am the president of HLAA-WA here and we say HLAA similar to AARP. So, we want to associate HLAA with the Hearing Loss Association of America.
It is an all-volunteer organization. We are affiliated with the national HLAA organization.
There's an organization in America and in Washington State dedicated to serving the interest of individuals who have hearing loss. Our community is diverse because hearing loss is a spectrum. You might just be starting out, maybe noticing a little hearing difficulty, but figuring out what all of that means or you might be more like me, someone who has had hearing loss their whole life and heart failure is deteriorating. From a spectrum of a little loss to a big lot.
Wherever you are on that spectrum, they are connected by shared experiences. We also have a shared goal of helping each other and helping our community thrive. HLAA-WA is working for you and with you.

So, before we get started, I want to make sure everyone can participate in today's activities.
First, this space is equipped with a hearing loop. In fact, all three of the event spaces and Town Hall Seattle is equipped with a hearing loop. If you have a telecoil in your hearing late cochlear implant or BAHA you can turn your hearing instrument into a telephone position program now and that will allow you to be able to hear more clearly and to hear with the hearing loop directly to your hearing instrument and this will block out background noise. We also have captions which you probably noticed. We have captions behind our interpreter here and we have captions above the PowerPoint presentation. You can also stream captions on your own device. There's a QR code link on your agenda.

Now you've noticed we have ASL interpreters near me to my right. And this is helpful to move closer so you can see the captions or the ASL interpreter.
Finally, I would like to add, this is what access looks like. Access levels the playing field for people with hearing loss and who are deaf. I encourage all hearing loss focus groups to do the same -- this is a model for hearing access. Assisted listening and captions and ASL make events successful for everyone.

Next, we had understood in our community that listening all day can be very challenging. When you enter this space this is called the Wyncote lobby and if you go through the lobby you'll find the Mehdi reading room which is a smaller space with seating and water available: Upstairs you'll find a great hall if you need a place to sit and take a breather. In the center of the hall there are restrooms with a unisex stall. The ladies are upstairs and the men's are up there to my right. There's an ADA we want you energized and comfortable and there's snacks at Otto's Bar and eat when you participate in today's program.
Now that we finished the logistics I really like to thank you for being here today.
We have been planning this event since January and every person on this list has played an essential role in bringing it to life. I can't thank each of you individually right now, but I want you to know that we are really grateful for your time and effort and energy and your care. This event is truly a team effort.

I also would like to take a moment to recognize all of HLAA-WA's volunteers even if it wasn't national volunteer month I want to say this. Our volunteers are incredible. Because of you, HLAA-WA reaches more people and has a bigger impact. When you serve on our board of directors and as advisers. Our help crew pictures here on the left -- hold on just a

minute -- somehow, I am missing this slide -- I'll keep going. We have a volunteer HOPE crew. They offer something very important to our community. Care support for people in every stage of the hearing loss journey. And then you advocate -- each of us advocate moving forward hearing freely policies and hearing friendly laws by supporting everything behind the scenes. Technology, fundraising events and more.

Now HLAA-WA could not be the organization we are without our volunteer force that helps us do so much.

To all of you -- thank you for giving your time and talents to the community. I would like to introduce to you Julie Johnson. Julie is our outreach coordinator. If you are interested in volunteering and we have many jobs, please see Julie and she has a signup sheet. I would like to give a shout out to our sponsors. Dr. Chad Ruffin and I am not sure I see him in the audience. But we want to thank Dr. Ruffin he's our ENT and cochlear implant surgeon and tireless advocate for people with hearing loss. If you have not seen his website he has helpful information. I would like to say thank you Dr. Chad. Dr. Chad has sponsored our lunch today so he would be very popular.

I would also like to thank the Washington State deaf and hard of hearing for providing the ASL interpreters who are with us today.
Thank you very much. Laurie, Jessica, and Cody for being here.
And of course, we couldn't -- we want to give our shout out to Eileen Horst who is our CART captioner today. Thank you very much.

I really want to thank all for taking time to come out today making this a priority for your Saturday. I know you have many other choices and other things you could do today. I want to thank you all for being here today. Our hearing loss community is all heart and soul and the driving force behind HLAA-WA. You are the reason we do this work. And the inspiration behind everything we do. I see many familiar faces, and it is really great to see y'all here today. We have quite a few new people joining us for the first time and really glad you are here. Let's meet each other.

As I mentioned earlier there's a lot of diversity in the hearing loss community and makes us strong. Diversity is our strength. Let's do a quick show of hands to highlight the perspectives in the room. You are welcome to raise your hand more than once. Let's start with raising your hand if you have hearing loss. Okay.

Please raise your hand if you identify as deaf or late deafened.
Thank you.

Now raise your hand if you wear a cochlear implant or BAHA device.

Raise your hand if you are a hearing health professional.
Okay. Over here. We have hearing health professionals.

Raise your hand if you volunteer or work for a hearing loss focused agency or organization?
Thank you, thank you for your efforts.

And raise your hand if you have a hard of hearing spouse, partner, friend or colleague. Thank you thank you.

And lastly raise your hand if this is your first HLAA-WA event? Thank you thank you. Welcome everyone.

(APPLAUSE).

Your support really matters. This is exactly the diversity here and is what our community looks like. Seeing all of your hands raised is a really good reminder that we may come from different places and spaces, but we face many of the same communication barriers. What connects us is our lived experience and navigating conversations, health care, school, work, family, in and out about in our communities, managing hearing fatigue, isolation, frustration, and sometimes exclusion. I also think that many of us share something else. An understanding that communication access is not especially pressed. It is our right.

I would like to take a moment to honor someone who is very important to our community and who is not here with us today.

As past HLAA-WA president and liaison Cynthia Stewart maze a lasting impact on our community. Cynthia passed away earlier this month and impact lives on. Because of Cynthia's leadership there are more hearing aids in more ears. More open caption movies in more theaters, more empowered consumers who know what to look for when purchasing a hearing aid. More people in our community know how to advocate. Not surprisingly Cynthia's awards are many. The Washington State association of the deaf -- golden hands award just last year. HLAA-WA impact award of 2024 and the national HLAA excellence and advocacy award in 2024 and the HLAA community service award in 2018.

Most of all we will remember her as a kind teacher, a thoughtful encourager and a wise leader whose work touched the lives of too many across Washington State.
Now Cynthia guided us to many legislative victories and helped passed hearing friendly laws with bipartisan support. She was our guide in Olympia tracking Bills and navigating procedures and moving legislation to the governor's desk. Her knowledge and patience kept us on track and without her we would not have hearing aid and greater open captions in public venues or consumer protection laws for hearing aids. The best way we can honor Cynthia is to keep on advocating.

The good news is -- Cynthia left us a roadmap. Cynthia knew that talking to legislators could feel intimidating, so she created a simple miracle way to structure the conversation. Using something you always have with you. Your hand. It helps you say what you need to say and here is how it works in a concise and effective way. This is effective whether you are speaks or writing an e-mail. We are going to take our hand on our thumb we introduce ourselves. I am Cheri Perazzoli and live in Redmond and am a constituent of the 45th district. I am here to talk to you about hearing access in health care. This is problematic for people with hearing loss. Explain why it is important to you. When I go to the doctor it is very difficult to understand when my name is called. Sometimes the information shared is hard for me to understand. I spend so much time struggling to understand what is said when I leave the office that I don't remember. It is important because the legislators and for other people -- why is it important -- that is our 4th finger. It is important because when communication fails, people are more likely to be readmitted because they don't get the information correctly. It costs our society. This is where you really make the ask. That is the 5th finger. Will you support the legislation and draft the

legislation and ask what they can do to support the Bill. Working with advocates we can have success using Cynthia's guide. What is wonderful way to keep her memory alive.

Okay we are doing a quick swap here.

So, I would like to show how HLAA-WA supports our community through advocacy support, outreach, and information.

Now you heard about the accesses already and building relationships with legislators. That continues every year and we provide support because as we talked about it hearing loss can be frustrating and overwhelming.

Connecting with someone who understands can offer real solutions and makes a big difference. Outreach is another part of our work we partner with agency employers and public venues to support other hearing communities. We share information from our website and social media and handouts the ones that are on your table today. The communication tips card are included in your packet. There are several tools that you can use anywhere communication matters.

You might be surprised that this month has been very busy for HLAA-WA and even more business next month. Nationally it is both Older American's Month and Better Hearing Month. It is also GiveBIG our statewide day of community giving and support of non-profits. All 3 really align with the work that we do in HLAA-WA. Older American's month is champion your health. It is all about wellness, prevention, and fits perfectly with today's theme, take charge of your hearing loss because hearing well and communication is such an important part of staying healthy, safe, and connected as we age.

That brings me to GiveBIG, our primary fundraising effort each year.

GiveBIG let's people invest in the kind of community we are building. One where hearing loss is understood and communication access is expected. Your GiveBIG donation helps HLAA-WA and provide support and information, expand community outreach and education and continue advocating for hearing friendly policies and law. Our giving begins Tuesday April 28th, and culminating in a 24-day of giving. Your packet includes a post card with a link and QR code. We are expanding our volunteer program with connections with communities and people are finding support through our work. Thank you for helping our community connect and thrive. So, yes -- wait for the mic. Wait for the mic please.

>>PARTICIPANT: Okay I want to tell people something and maybe everybody here knows it. Maybe one person doesn't and should know. It is that if you are retired and take I money out of your IRA or retirement thing you can subtract that and pay less taxes.

>>CHERI: With the donation.

>>CHERI: Thank you Diane. That is creative inspirational donations, and I'll be happy to learn more creative ideas from you on that.

Moving onto our program to help you all and myself and help us all take charge of our hearing loss we planned a full day. I think you'll find it really engaging. You'll find practical education and opportunities to connect and tools that you can start using right away. Our program includes -- to get us started to is my great pleasure to introduce my dear friend and colleague Ann Thomas. Come on up. Ann has helped with many roles for HLAA and worked on the

hearing loop and many leadership roles and the HLAA California association and an a- at hearing loss advocate with deep expertise in community gathers and assistive technology. Thank you for being here with us today.

ANN THOMAS: KEYNOTE

>>ANN THOMAS: Thank you Cheri.
I am so happy to be here today. I was thrilled and honored that HLAA-WA thought my voice was important for all of you here today and what I have to say made to fit your life. The theme this year is take charge of your hearing loss.
That may be a difficult thing, it may be a long process. But it is how you will live your best life with hearing loss.

I found out that I was losing my hearing in my late 40s. I have a progressive hearing loss. Today I have two successful cochlear implants. As Cheri said, I came up here and live in California, and so this is an extra treat for me to be here today. One of the things that I've learned in my hearing loss journey has been that people with hearing loss live uncertain lives. We never know when we are going to able to understand and when we won't. We all have a tendency to think that we are doing better than we may actually be doing.

We have a tendency to think about how we function on our best day in the best situation, rather than how we function when things go awry.

I would like to remind everybody how important it is to really embrace that concept. As Cheri mentioned, we are entitled to communication access in a wide variety of circumstances throughout the United States.

If you ask, don't ask for the communication access that you need, because you are thinking, oh, I am doing just fine. You are not thinking about the worst-case scenario. What happens is, it is too late to ask for it if you find yourself in a situation where there's loud background noise, someone has an accent, there's some other thing that interferes with your ability to hear. Maybe there's a compressor in the room or a medical point. I want everybody to embrace the advocacy muscle to ask for what you need before you go to an event based on your experience on your worst day. If something happens and turns out, you can hear just fine. That is a day to celebrate! Hallelujah! If it is a day when everything goes south and you didn't ask for your communication access then it is a miss. I don't want people to feel guilty. We have the guilty thing that is terrible and feel guilty that you asked for something that you really didn't need on that day. You are just taking care of yourself.

Hearing loss is a spectrum disorder. Cheri already asked everybody to raise their hand to indicate who was present in the room. I identify at this time as late deafened. With my cochlear implants, I am hearing in the 90-decibel range, and I have zero speech recognition and my speech recognition is 70% and I am still a hard of hearing person. Last night we had a rehearsal and had a hearing loop in the room and celebrated dinner together. When we celebrated dinner together we didn't talk one-on-one and the noise level in the room rose and I was using my speech-to-text app on the phone.

I would like people to raise their hand if they have had their hearing tested?

So, who in this room might be easier -- hasn't had their hearing tested? Okay that gives me an idea of who I am talking to.

How many people wear hearing instruments? I am choosing to use hearing instruments. Three kinds. Hearing aids, cochlear implants and bone conductive devices. To say all of those over and over again is a mouth full. Hearing instruments covers all of them. How many people in this room wear hearing instruments? That's almost everybody.
Thank you very much.

As you all know, hearing loss is common. We don't have any national census on disabilities. When you take a census they don't tell you what your disability is. We don't have accurate figures of hearing loss. I use a conservative figure of 1 in 5. Common is heart disease and arthritis. I have arthritis and nobody seems to have a problem talking about their arthritis, but most people have a huge problem talking about their hearing loss. The most common hearing loss is called neurosensory hearing loss in the high frequencies. If you look at this audiogram you'll see that in red, it says high frequencies. Within that range there's also a circle. In that circle are the letters S-T-H-F. These are the consonants and the phonemes that help us understand speech. Once you have a high frequency hearing loss to understand what other people are saying. Imagine I have been living in a world that sounds like this. This can easily be our world.

So, in this example, the letters STH are missing. If you are listening to someone communicating then, you are trying to figure out what those missing letters are.
Speech lib reading can be of assistance, but everybody needs to know lip-reading and speechreading is not 100%. There's only 20% of sounds that show on your lips. The original language was lip-reading which is reading only lips. Now it has expanded speechreading because we show sounds of inflexion of our throat.

Where do we have problems? We have problems communicating with friends and family. Communicating in noisy environments and understanding the TV, on the telephone, in a lecture or during virtual meetings. It is really everywhere.

And even though it is a physical disability, it affects our total well-being. It effects our relationships for those of us who have partners we know how difficult that is on them. Sometimes we can hear them and sometimes which can't and sometimes we have hearing instruments in and sometimes we don't and when we don't we don't have a sign that says I am not connected. We have partners that figure out they start the speech-to-text app and flash it at us and remember we can't communicate with them when they are talking to us. It effects our self-esteem. Those of us born with hearing loss have people make fun of them their whole lives and it affects us. I was fortunate since my hearing loss was late in life I have personally not have experienced much loss of my self-esteem and in some ways my hearing loss has given me a benefit and gift to be able to speak out and speak up in public. Our social interactions and daily activities and going to the grocery store sometimes it is impossible to understand the checker. Other people's perception of us.

We also experience overload, hence in this room today this event there are quiet spaces two quiet spaces because it gets to be too much. We are spending so much effort trying to understand. If you need the quiet space today -- please use it. We end up fatigued. I've been very busy since I've been here and came up early because Cheri and I are friends and we were running around making this event a success. We've been with other people sharing and preparing at the end of every evening I've been exhausted.

Some people experience ridicule. Ridicule from a young age. I can share an experience of being ridiculed doing outreach events. Now the people who were ridiculing me were thinking they were being funny. But when you walk by a hearing loss booth when you are trying to

educate people and help people and people are going huh? Huh? It is not a supportive feeling. Something that has come up in recent years from research that has been done at John's Hopkins they are finding a link between diabetes and hearing loss. The hope is if we get the hearing instruments that we need and use them it will diminish the likelihood that we might be impacted by the lack of stimulation of our hearing that contributes to dementia. Many of us know what it is like as our hearing diminishes and we have more and more trouble in spaces where there's background noise. This can be social isolation, loneliness, depression and also there's a link to falls. This is because the inner ear controls our balance. Some of the inner ear bones get out of whack in relationship to our hearing loss and some people have increased balance issues.

I find this particular quote from hearinglossmom.com to be especially important to us. I don't think many of us take into consideration that we might be developing additional important skills and abilities. Hearing loss is not just a disability; it is a way of life that requires a different type of strength. Different things that we have to use. We have to learn how to advocate for ourselves and speak up and speak out.

Hearing loss is also a journey. I've likened what exists today in relationship to hearing loss what existed in the 50s in relation to talk about mental illness or saying the word sex in public. There's a huge stigma around hearing loss. It is not talked about on the news and not obvious everywhere. There was a national campaign to stop smoking and they accomplished that. Susan B. Komen against cancer. It is our goal to reduce the stigma for ourselves as well as others.

To live your best life, you have to move from place to having shame about your hearing loss, shame because you have to ask someone to repeat something once, 3 times, 4 times it is embarrassing to acceptance. Oh, that is just the way it is. There's nothing wrong with me. I am a whole healthy person; I just have some special needs. And asking others to help you with that.

We live in the best time that anybody could possibly ever live in relationship to having hearing loss because of the technology available to us at this time. Digital programmable hearing aids were invented in 1996. That is not that long ago. Before that time, all hearing aids were like Pocketalkers, they increased all sound. Today that is not the case. Today they adjust each frequency area where we have a deficit.

If you hear people talk about oh, my grandparents they had hearing devices and terrible and never wore them and on and on. The hearing we have today is not those aids. To have problems with your hearing you need to go back to your hearing health professional so they tweak the program so it can be the best it possibly can be:

2005 is the only time streaming of hearing aids. It was via streamers and boxes we wore around our neck. The reason for that is because the space and speed of Bluetooth at that time drained the battery on the hearing aid that they couldn't work well and they couldn't integrate that. We had a problem with the streamers and when we use the Bluetooth after a couple of hours we had to recharge them. 2024 there was a game changer. Hearing aids from Bluetooth integration because it advanced so that it could be integrated into the hearing aids.
For most of news this room that was a huge game changer for us because we could use the telephone better with our hearing instrument because we stream via Bluetooth.

2024 marked the introduction of the first hearing aids premium hearing aids that use AI and one of the areas they are benefiting people who are able to use those hearing aids is that they are more effective in diminishing background noise than anything that has happened previously. I've never used an AI hearing aid because I got my first cochlear implant in 2022. They were introduced after that.

There is a new expanded form of Bluetooth. Bluetooth special interest groups home is here in the Washington area. All major corporations in the world belong to Bluetooth Sig.
One of the reasons they belong is because the Bluetooth technology is licensed. The hearing aid manufacturers approached -- who remembers special interest group and could see this if they could make a universal Bluetooth and make it so it could stream audio. They have successfully done that.

This new form of Bluetooth is called Bluetooth LE audio broadcast. The name for the upcoming assistive listening system is called Auracast.

So, the time period for Auracast to be beneficial for all of us can be quite long. Assistive's have been installed. The Sidney opera house has Auracast on top of hearing loop and with Auracast you need to use a receiver unless your hearing instrument is already enabled. There's some instruments today that are Auracast capable but not been enabled. This is a whole process moving forward. Auracast was not invented just for people with hearing loss. It is invented to improve communication access for everybody. People without hearing loss cannot understand at the airport either and Auracast is going to be everywhere.

Just because we have hearing instruments doesn't mean and we can understand there's sound -- doesn't mean we can understand words with cochlear implants or hearing aids. One of the biggest myths for people is that hearing aids fixed hearing like glasses fix low vision. That is not true. Hearing instruments are a tool, and they help us and make it easier, but they are not 100% solution.

The basic rule of thumb about hearing aids that most people don't really know is that they really do not have a long effective range. The effective range is as short as 6 feet. If I put my arm out and you put your arm out that is about 6 feet. For many people it could be a 6-foot radius in a quiet radius situation and can work with that.

Optical speech comprehension. Most people do not understand if there's a public address system that many of us cannot understand. The reason is because the speakers for the public address system may be in the ceiling which is further than 6 feet away.

Reverberation or background noise or echo. Not much attention is placed in this country to acoustics and that is changing with the LED movement to improve and making accessibility in general construction.

Competing background noise and face masks. I don't know what I would have done during the pandemic the speech-to-text app. You think face masks are over. In the San Francisco paper last week there were 3 other respiratory diseases that are swamping the San Francisco Bay Area, and they were talking about face masks again. It is not going away. It is a real obstacle for us.

What else? What do we do, right? People go from challenges to possibilities -- ways of improving our lives. Hearing loss effects how we connect, communicate, and participate. No single solution works for everyone. I would like to say at this time they find how we interpret sound is unique to each one of us like our fingerprints. You can have two people with the exact same results on their audiogram. They prefer different adjustments on their hearing instrument.

There are tools, technology, and know how to make life easier for all of us. One of the problems that can happen for those of us over 60 is you may not have grown up with a lot of technology today. It is a little bit intimidating to figure out how to use those technologies. In my area I am there to help with anybody who needs help. HLAA-WA is here for all of you. There's people throughout the room with name tags on and some have iPhone and some have Android. My next presentation we will talk about apps on your phone. Look for one of us with proper designation and during both breaks back here in this area there are people wondering around and people at the tables to help you download the apps I am going to talk about.

How do we overcome the obstacles? Through acceptance. Accept where we are and who we are and try to figure out what we need.
It's my opinion that if you are not using the app or hearing instrument made by the manufacturer on your Smartphone as a remote control you won't get the best use out of your hearing instrument and live your best life.

There are caption telephones and speech-to-text apps, and assistive listening systems like in this room a hearing loop, but I am not discussing those today.

I brought two brochure pieces of publication one on your table for a phone app called InnoCaption and they have a really nice brochure that allows you to see how you can use captions with your Smartphone. Captions can also be used on your laptop and desktop and there are caption telephones. What are your next steps? You haven't had your hearing tested and you noticed something. Even if you don't everybody over 40 should get their hearing tested. That is my personal opinion. It is not on your list from your doctor of things you need to do. Get your colonoscopy and mammogram.

Some people put their hearing instrument in the auto program and doesn't know there's other technology that can help them. Learn to advocate in everyday situations. There's a session after lunch about that.

Connect with HLAA-WA and there are a lot of people who want to help you in the same situation you are. Based on your life experience how to make it better. Share what you learned from your family and friends, so you start to develop if you don't have it now empathy and understanding. That's the key to our well-being too. Our friends, colleagues, and family members can't be mind-readers. We need to tell them what we need. We also need to practice good techniques with them. If we want them to talk to us face-to-face because it is easier for us to understand them. It is not a good idea if we talk to them behind our back because we are not modeling good behavior. Makes sense, right? I would like all of you to take charge of your hearing loss. I personally believe that all of you can do that.

We are going to take a 15-minute break and during that break if anybody has not downloaded the app and I went from table to table before we started to try and help people if they hadn't done that. I talked to people at tables who have already done that and willing to help others at their table if they needed assistance. Make sure you have that app on your phone before you leave here. There's a packet on each of your tables. The information packet how to use the

hearing instrument remote controlled and a little case at the end about CO_2 and smoke detectors. At this time, I would like to invite all of us to go ahead and take our 15-minute break.

>>PARTICIPANT: Could you please explain which app you are talking about that you would like people to download?

>>ANN: If you look at this form -- it is on everybody's table -- every hearing aid manufacturer -- it is a mistake to say every. To the best of my knowledge most hearing aid manufacturers have an app today that works with your hearing instrument, and you use it on your cell phone. This app acts as a remote control for your hearing instrument. I'll say this now and repeat it again in my presentation. The reason this is so important to us is because as hearing instruments have gotten improved someone got the idea to remove one button. We used to have two buttons on the instrument. One for volume and one for changing your programs. I love technology. I am very dexterous and I have a problem with the one button system. I think I am trying to move to a program, and it is a tap for volume and a hold for the program. You know -- the difference between those two is slim. Especially if I am not hearing well and I get flustered. If you look at it on your cell phone you can see everything in English. So no need to be confused and my technology doesn't work right, and hearing is not working right things tend to snowball. Is that helpful? Anybody who doesn't understand about what the app is? Okay. If there's somebody who is shy and doesn't understand that, please visit Carolyn, Heidi, other people around here and go back to the tables over here and demo tables and people in the front lobby. Everybody is here to help you today. Thanks and enjoy your break.

(A break was taken for 15 minutes).

Everyone take your seats so we can start the next presentation. Thank you.

ANN THOMAS: HEARING TECHNOLOGY CAN BE YOUR FRIEND

>>ANN: Now we will begin the component of our presentation today talking about actually the technologies.

How many people in this room use the -- in our session yesterday we were planning this out -- we wanted to make sure everybody understood what we are talking about. The hearing aid manufacturer app -- it is made by your hearing aid manufacturer is specific to your hearing instrument -- the app on your cell phone as a remote control.

Some. Okay. The value of using it as a remote control because it makes it easy to select the programs that you are in and adjust the volume, and depending on the app, some of them even today have an equalizer built into this to adjust them if you listen to music.

So, why do you need to use a hearing instrument remote control on your app? Before the break I already talked about the fact that hearing instruments have moved from two buttons to one button. I find this one button to be really difficult especially when having a hard time hearing.

I got my hearing instrument during the pandemic and there was no background noise. My husband's brother passed away and everybody was so upset and his family is from Charlotte, North Carolina and we went back for the memorial service. I didn't want to cause any anxiety or

disturbance, and I chose not to advocate for myself before the event. I didn't know if I was going to understand his memorial service. It was in a huge old church in Charlotte and no carpeting and a massive place. I walked up to the church and saw a hearing loop symbol. I thought "How great is this." I didn't know I was going to need it. The minister started speaking and there was so much reverberation that I couldn't understand them. And then -- I actually didn't want to pull out my cell phone because I was in the front row with family and there were over 500 people at his memorial service and I didn't want people thinking I was reading my cell phone. I took a deep breath and thought okay which place is the T-coil on and what program is it on and how many buttons do I have to push and is it tap or do I have to hold it? Unfortunately I found my telecoil program but I had the anxiety on how to do that. I've never forgotten that and try to avoid that at all cost.

That is why I am advocating for everyone to have it on your phone and be able to use it. Most people don't realize that most of their hearing instruments can have multiple programs. I talked about the transition and technology. Most of us today have an automatic program and the idea behind this automatic program is that it's going to be able to adjust to everything behind the scenes and you may not need another program.
The reality is most of us still find some situations that we like to have additional programs. So, I have a telecoil -- automatic program, telecoil and mic program, speech in noise program, and a special program with masks during the pandemic that made the central voice louder. In situations I need to be able to change that program and the easiest way to do that is with the app.

You also can quickly and easily -- that was very funny. I have a magnet on my watch and it stuck to the podium because it is metal.

You can easily adjust the volume. You can see in the slides later. You can understand speech understanding without touching your instruments. I talked about what hearing instrument programs are available. We have the auto program, the telecoil program in most of the apps has the ability to adjust the balance between surrounding sound and telecoil. Why that's important is because in loud environments you want more telecoil and less surrounding sound. If you would like to be able to talk to the person who may be sitting next to you, you need some surrounding sound to be able to hear them. Some of my chapters come to the meeting and put it all on telecoil because that is easier for them to understand. We have a hearing loop and runners that pass microphones for audience Q&A. You want to be able to do that. Speech in noise in restaurants have the ability to be able to adjust what it is focusing on. Surround versus focused -- you can even adjust the width of what it is focused on. Today, I am not interested in having you understand these more advanced features. I just want you to be able to have the app on your phone, be able to change programs, and be able to adjust the volume, and to build on that as you need it. You don't have to learn everything all at one time.

>>JACQUI: Something I've noticed is that people have trouble being a squeaky wheel in terms of going to your audiologist and say I don't know how to use this particular program app thing on my phone. Can you speak to that and encourage people to go back and get the help? Or come to meetings like.

>>ANN: We have audiologists here today and they have patient care. I hate to tell all of you I have not been successful, and my chapter members have not been successful to get the audiologists to teach them how to use the Apps and accessories that are available for their devices. So, that is why we are here. That is why Hearing Loss Association of Washington is here, and hearing loss has HOPE meetings online and you can attend those and maybe somebody would be there like Heidi or Carolyn and make an appointment with them at another

time. Devices can help you connect to the TV, and some have a remote microphone. Some have additional devices and a portable microphone and using the microphone in your cell phone.

You can have a program for the car -- a special program to help you understand in the car or music. Music is one that a lot of people want. That would be a special program designed to expand the range to include music. We have two questions here. Can we hold them until the end? Thanks.
Try to remember!

The place you download the app is in the Apple store or in Google Play. It is on the sheet that each of you received on your table are links to different apps and I'll talk about that in a minute. How to download the app. We are here to help you in the next break or any time after that look for someone who has Android or Apple on their name tag.

Of course. There are only 5 major manufacturers in the world. I've only listed the major manufacturers here and added Philips because so many people have Costco hearing aids. These are not an inclusive list of all hearing aid brands. These are the logos on the side. For Oticon if you have an Oticon hearing aid the name of their app is called Oticon companion. Some hearing aid manufacturers have the ability to do remote programming. This movement toward being able to do that really was a direct result of the pandemic. I've had one remote programming and I went with -- with cochlear implants rather than saying programming they say mapping. I had seen my cochlear implant audiologist, and it is a special kind of audiologist. I had a maps session. My app did not get updated correctly on my phone and I couldn't adjust my CI's after I got home. I texted her and the next day -- I live -- to get to my appointment in San Francisco I need an hour and 20 minutes each way. I wasn't very excited about doing that because I had done it the day before. She sent me a link and did it right from my office. That is one of the advantages of having the ability to do remote programming. As you read down the list which is also on the piece of paper that you have with you. You can take it with you. You don't have to remember it all.

CI apps. There are 3 major CI companies in the United States. Advanced bionics which is owned by Synova.

Their remote programming with my audiologist is called remote support. You are probably with the Phonak Roger system. If you have the Roger system there's an additional app to be able to make adjustments to Roger.

Cochlear America has nucleus smart and MED-EL which I am not familiar with also has audio key. It is my belief to get the full benefits of your hearing instrument you need to become fluent in the app. How to use it, and use the right program for the right place. In using the right program for the right place it can be trial and error.
So, you may try one program that says speech and noise but in that situation with acoustics in the room it didn't work well. Go back to your auto program and then you can say if there's a super noise program. I have a program that is a speech and noise program for extreme noise like if you are in a bar or convention or something like that.
We all have accessories. Some people get their hearing aids, and you get a box of accessories. I made house calls in my community. If there's any person in my chapter having problems with technology I'll go to their home and help them get connected. People have all of these accessories and have never been taken out of the box. They have no clue how their life could be enhanced. I am inviting all of you to look at what you have in your boxes and see what's

there and if you have questions about them, contact HLAA-WA association. You are a part of our community, and we are here to help.

One of the devices is a TV connect. With my CI's I can understand the television but have to work harder. With my TV connect it is like nothing. Now some of the new TV's don't have a digital audio port. If you happen to find yourself in that situation, there's an adapter that is sold that will transition between HDMI and it has to be arc and digital audio for your TV connects. That is a tricky thing. Heidi -- I am sure Heidi would be able to help you with that.

>>HEIDI: Thanks!

>>ANN: Some hearing aid manufacturers have enabled the ability to use your Smartphone -- a microphone in your Smartphone -- as a remote microphone. This is a very small list. There's a full list on the Apple website. Because of the -- made for I phone feature -- created by Apple. Cochlear and MED-EL both have that. Carrying accessories around can be problematic. First of all we are always afraid we are going to lose them because they are little and I know the Roger is between $1,500 and 2,000. It is not a little thing. If you have the capability of a microphone you can activate it right from your Smartphone. I am jealous I don't have that feature.

I chose to pick some examples of what some of the apps look like for some of the major manufacturers so that you all can have an idea of what they might be like. These are images from Oticon. If you see the image up in the right-hand corner where it says change programs with the arrow -- Oticon uses the term universal and that is your auto program. You touch it or slide it and you can change your program. There are slider bars for volume and you might be able to adjust the volume in one ear or the other ear or they might be joined and you may be able to ask your audiologist to give you the option to do that.

You also have other custom settings in the bottom left-hand corner, and the bottom right is a sample of what an equalizer might look like. I chose Philips because they get Costco hearing aids. Their app is called hear link and this is what it looks like. I run into people all the time who have hearing instruments from Costco and they don't anything about the features that are available to them with their instrument or how to connect their devices and things. So please, reach out for assistance to expand your ability. We want you to function the best you can. To have the best life. To do that, we need to be able to hear the best we can.

This is what Phonak looks like. There's a place where a lot of the apps where you adjust the programs is at the top. It is the first thing you see and a slider sometimes it goes up and down. Some of them across the bottom have different selections or options.

And star key. It has a my link to remote program.

Is anybody here getting the idea how valuable it is for you to be able to use this app?

(APPLAUSE).

WIDEX is different than other companies with the app. The other companies have a single app for their hearing instruments. Star key have apps for specific models. You need to go and find your box of stuff again with -- everything came with some kind of manual. On the manual it should say what model of hearing aid you have. For WIDEX their current model is called Allure, moment, evoke, and older models are beyond.

Allure and moment and evoke you can download on the app store. You have to go to the WIDEX website and some of the old Android phones may not update.

This is advanced bionics that I have and this is simpler than some of the other apps. The other apps give you more options to be able to adjust things. I don't have the ability to equalize sound for music.

The image in the center is what an adjustment could look like for telecoil. On the bottom there where the arrow says adjust telecoil there's a slider there. You slide it to the right and you are increasing the telecoil. Slide it to the left you increase the outside sound. You are looking for whichever situation you are in, that you are able to adjust it the best you can. My experience in finding out the importance of this surround versus telecoil mode, happened when we were piloting hearing loops for our mass trance sit in the Bay Area rapid transit. There were 40 of us testing one of the locations. Richard McKinley came out to run the pilot. Most of us did not have apps on our phone and they didn't exist. People had -- most people had only one telecoil program. That telecoil program was the microphone which was the surround sound plus the telecoil. I had 3 on my hearing aids at that time. One was all telecoil and one was telecoil and mic for surround and one was just for the telephone. Most of the people on the train had a hard time with the hearing loop and thought it didn't work because they had microphone surround plus telecoil and the train station was so loud that the sound they were picking up from the microphone was overshadowing the telecoil. I could switch between my two programs when I was in telecoil only and it was perfecto. I learned first-hand how that balance can effect you. I am shifting now from the app which is for your specific hearing instrument to additional technologies that can help you.

One of them is captions for phone calls. Captions for your Smartphone. Almost everybody has a Smartphone. Everyone is ditching land lines even though there are phones available for land lines for Clare captions and Hamilton Cap-Tel.
Even though you may be hearing most of the time really well with the Bluetooth connected from your hearing instrument to your phone. It is not always great. Once again you really need to be prepared.

If you are having conversations and streaming wonderfully through the Bluetooth and device and phone and understanding everything, there's no problem just continue hearing and listening. But let's say all of a sudden -- there's a bad connection. Let's say all of a sudden another person came on the telephone. Let's say you were calling customer support and the first person was fine and transferred you to somebody who had an accent. After you waited 45 minutes on hold to get to them, the last thing that you want to do is to hang up and call them back. So, if you had the captions on your cell phone, all of a sudden you could just start using it. You could start reading what these people were saying when you couldn't understand them. I have found them to be really pretty accurate even with accents. I know sometimes one of the hardest things for me is numbers.

1, 2, 3, 4 and somebody says 5 and I can't understand 5. What is the one after that? You don't have to do that because you can read it all. It is really wonderful. Everybody has a brochure from one of the premier companies in America that has caption phones called InnoCaption. I asked for them before I came and broad one for everyone here and see that option and decide if you want to download it. They are not the only game in town. There's also caption called Clear Captions Mobile and Hamilton Mobile Cap-Tel.

InnoCaption did a survey of people who used caption with their cell phone decreased listening effort by 49%. Wouldn't we welcome that to have a little less stress?

Before we leave here today I want to absolutely make sure that every single person in this room understands the speech-to-text app, has chosen to activate it or not, and I am encouraging everybody to activate it. I absolutely cannot imagine my life without it. You have your Smartphone, you turn on the text to speech, and it captions exactly what you are saying generally.

So, last night when the sound got too loud when we were in our rehearsal -- none of my technology worked. So I turned on my speech-to-text I don't know why I am -- and it captioned every word.

In Apple it is called -- go to your settings and it is under accessibility -- I visited tables helping them get that online beforehand and on the break. It takes 2 seconds. I am happy to do that any time for the rest of the day.

You go to settings -- accessibility -- hearing. Turn on live caption. Android has -- they were the originator of live captions on your phone. They have an app called live transcribe and there are additional apps speech-to-text. One of my favorite is called Ava and not the simplest to use but the most robust. I'll give you an example of its value. During the pandemic, we had a 6-foot limitation of contact, right? Most of the time the speech-to-text apps worked the best the closer you are to the microphone on your telephone. Also be cognizant the microphones are on the bottom, and we tend to hold our phones like this. What happens is you are covering the microphone. I also have multiple stands at home that I put my cell phone in the stand, so I am hands free. What you can do with Ava getting back to Ava -- is you can have multiple people with their own profile in the same conversation.

The limitation of distance is removed. I could theoretically, Ava with Cheri from my house in California.

What would happen is in the window that you are looking at -- see here this image on the screen -- at the top you see two profiles. One is a person's picture, and one is another round circle. That means two people are connected to this conversation.
I believe you can do up to 10 people, and I think it does 54 languages. So what this -- during the pandemic or any situation like that as long as the two people are connected to the app the distance doesn't matter. If you walked into your hospital like my hospitals and they had you stop here and purify your hands and make sure you have your mask on and then they are 6 feet away -- sign in something and they are 6 feet away talking to you and there's no way you can understand them. The distance was further away from the regular speech-to-text app. If they had Ava talking into your phone and their phone you could be 20 feet away. If anybody is curious about that later come and talk to me. This is what live captions are on eye phones. Settings -- accessibility -- hearing -- live captions. That little black box at the bottom can be wide and narrow, full screen, or closed. When it is closed it is a floating button on any screen you ever use. Last night when we were talking, Heidi said it drove her crazy about the floating screen because you are moving it around when it is in the way. I have adjusted to that, and Heidi found a different app she likes better. The one she likes better is called the Big Text. There are a lot of ones you can use. This is Android live transcribe. I don't have an Android telephone, and I can't help you with this but there are people here today who can and they have Android written on their name tag. Live Transcribe was the precursor and number one speech-to-text app that was native to the cell phone and part of Google to do this.

The last thing I am going to talk to which effects all of our safety.

Most of us are really lax in acknowledging how important this is.
You live in fire and earthquake country and I live in fire and earthquake country. These happen all the time. We need smoke detectors and carbon monoxide detectors that wake us up in an emergency.

Smoke and carbon monoxide detects won't do that. It is hard to imagine the shrill and piercing and disruptive sound we may not be able to hear to wake us up in enough time in an emergency.

It's 3 minutes. So, if you are taking a nap in your living room in your recliner and you took your hearing instrument off -- SOL -- you are in why you are bed and you happen to be sleeping wrestling around all night and pillow over your head -- forget it. You have one ear better than the other. You had the good ear down. There are many many reasons why we couldn't hear that. There's special devices made for us. The picture here are of two that are not hard wired.

Many of the professional level devices are hard wired. Which means you have to have an electrician come out and install it unless you are an electrician or something like that. One system is made by bellman and Symfon and we have brochures at the tables. Sonic Alert has been on the scene as an American product. I have Sonic Alert because at the time I got mine, you only had to add one additional device to alert for smoke with carbon monoxide. At that time, it was only for smoke. Today -- it is a Swedish company bellman and Symfon. The design is super fun and clean. You need to buy two accessories. One for smoke and a sensor for carbon monoxide. So that I can continue educating myself maybe you guys are going to surprise me.

How many people in this room have smoke and carbon monoxide detectors for people with hearing loss? See! Not very many. All of the rest of us are at-risk. I am telling you I would be really irritated if something happened to me with smoke or carbon monoxide that I could have prevented and I lived. I would be really mad. That ends my presentation this afternoon. I think -- do we have time for a few questions? Heather is not here we have questions and answers -- anybody have -- it is right here on the table. I hope this has been helpful for you.

>>PARTICIPANT: Hi, I just wanted to add that I think we also need to advocate with our audiologist because I think they should be doing more. Recently -- it is very hard to get an appointment now. I had to be one of those squeaky people. I just paid $5,000 for hearing aids. I am used to having an audiologist that will respond to me. It wasn't happening. I really complained about it and connected with my audiologist and found a way to get in touch with her. We need to say -- they need to provide these thing when we go ahead and purchase hearing aids at least classes or something.

>>ANN: Not that I disagree with you at all and 100% support your opinion. The reason we are all here no matter what we have generally done, somehow nobody is listening to us. So because nobody listened to us we wanted to help other people in our community. I agree with you 100%. Can you stand up to make it easier for people?

>>PARTICIPANT: I would like to piggyback on what Donna says. I use cochlear implants and I use hearing aids. He paid $6,000 and went back to his audiologist and she gave him to a support person like a PA in the office. She doesn't spend her time teaching the apps. So the support person got very defensive. It is a really good app. Reminded me he had brain surgery and said I am in pain. The surgeon said my God look at this perfect X-ray. That doesn't cancel out pain. A PA who gets defensive is not the right person to be teaching somebody how to use a system. So I've asked him to go to a different audiologist, and we will tell the person why. I just want to support what you also said.

>>ANN: I encourage you to write the VA. They have meetings. I believe if you have problems getting an appointment with the VA you can go within 60 miles of where you live. Don't quote me on that. Some kind of thing like that. If somebody knows the exact information can you please provide it. There are other options. We are in agreement.

>>PARTICIPANT: Hello -- my name is Jim House, and I am involved with emergency planning for the State of Washington. So I wanted to point out about the smoke alarms and the CO_2 alarms.

We have several options to get one. You just need to reach out with your local fire department or the American Red Cross.
They do provide a clock that you will audibly be able to hear and another alarm in a different building. You don't have to be in the same room it is connected to that clock, and it has lights or vibration depending on which device they provide. So check in with your local fire department or the American Red Cross for those.

>>ANN: Jim, I have a question for you. American Red Cross in California only provides a detector for smoke. By law in California, we are supposed to have both. The Red Cross here in Washington can be different. Can they provide for smoke and carbon monoxide?

>>JIM HOUSE: Some do have audible system T 3 or T 4 or something like that. It is a standard where it picks up a specific frequency and does have both. Has the smoke and CO_2.

>>ANN: You all are rocking. Thank you Jim for making sure that everybody knew how to get what they needed in the State of Washington. Do we have a question back here?

>>PARTICIPANT: First of all, thank you for your presentation. I have Oticon hearing aids that are over 4 years old. I'll probably need a new set. Mine has 4 programs. What do the new ones -- how many programs can you get with a new hearing aid? Is they told me that is what you got and no more.

>>ANN: I am not fully qualified to answer that question. I'll answer it based on my knowledge and experience. The audiologists who are here may be able to give more information about that. What's happening with the programs is a number of programs seems to be staying kind of stable. But the changes that you can make to those programs is increasing. Does that make sense? Being able to -- you would still have the same 4 programs but being able to use an equalizer with a program will help you with that.

>>PARTICIPANT: When I am at a live performance group I don't know what my preference will be before the performance starts. Yet after it starts when I realize what I settled on is not correct, I don't want to be using my phone to distract other people in the audience or performers with the light on the telephone. Do cochlear implant and hearing aid manufacturers provide a non-phone option like the old remotes for adjusting your preference, so you don't distract people in public?

>>ANN: To the best of my knowledge there are still stand-alone remote controls but all they control is volume, and the program. You don't have the ability to adjust the balance between telecoil and mic.

I said I wasn't going to talk about assistive listening systems. The ADA requires any time there's audio amplification in the room that the room is required -- audio amplification like a PA -- they are required to provide assistive listening system. There are generally 3 systems a hearing loop

which is in this room -- and the reason we like that so well is because we have clarity of sound and we don't have to ask for another piece of equipment. We put our hearing instruments into the telecoil mode and it automatically connects to the system. With both FM and it is radio frequency -- it took me a long time to understand this. We have AM and FM radio it is like that but a special frequency that is reserved for FM systems: That requires everybody to have a receiver through the hearing loop the hearing receiver is built in. How do you connect to that receiver? Headphones generally don't work well with hearing instruments. I am not saying there aren't any headphones that work. Some higher end ones with bigger muffs can work. That is not what they give you. They give you cheap headphones that slide around. They give you telecoil that you can use in other systems because the way you connect is with what is called a neck loop. The neck loop plugs into the audio port on the receiver, and it goes around your head and you put your hearing instrument in your telecoil program and the sound is in the middle of your head clear as a bell.

Now, your issue about feeling uncomfortable using your cell phone may be a way you are going to have to fiddle around about how to be more discreet about that or as discreet as possible. It may be the only answer. This gentleman right here.

>>PARTICIPANT: My name is Earnest Covington, and I am the director of DHH deaf and hard of hearing in Washington State. The telecommunication we distribute we encourage people to apply or smoke and CO_2 detectors and we are more than happy if you are interested we will provide those for free. I have an application that you can fill out, and it is on the ODHH website that you can complete. Anybody with a disability can apply and we are more than willing to provide those.

I do know before there was not a lot of option will to get the CO_2 and smoke together. I have applications that I am willing to handout. The other question is Ava and I use it myself. I struggle in a large setting like church for example. Ava has a hard time picking up on those voices and is there a way to use Ava and it doesn't identify people in those settings and how can I make it more available.

>>ANN: The issue with speech-to-text apps is the distance you are from a microphone. So a speech-to-text app is not excluding. It is not to be used for something at a far distance. You are talking about your minister talking on a podium at the front of the church. Well, the microphone is too far away from him. Now, you could ask your church to install an assistive listening system, and you can ask church -- a lot of them have big screens and they run the hymns on the screens, and they already have the equipment to be able run captions there. They are just not doing it. Another option you could do is if you were inhibited -- you are the director of the organization, so I hope you have the advocacy muscle! Give the minister potentially a Bluetooth microphone that was connected to your cell phone. So that's wireless and the minister -- you wouldn't be able to hear the other stuff but at least you could hear the sermon. He could be wearing the microphone, and it is to your app and that could work. The new eye phones don't have an audio jack. You need to purchase an accessory item which you can get from Amazon which I recently did for something else. I encourage you -- don't get the one that just has an audio jack. Make sure it has an audio jack and a place to recharge your phone. You can't use the microphone and recharge the phone at the same time if you only have the one port. Does that help?

>>CHERI: I wanted to add -- do I need a mic? I just wanted to add a question back to Ava ask his minister to download the Ava App?

>>ANN: He could. The piece that is more difficult in this situation the minister is at a pulpit -- where is he going to put his phone? Ava is unique where they made it that you can rotate. The Apple app you can't rotate. Let me see if I can get this to work here. Here is my Ava app and it is connecting. Here is my microphone down here he. During the pandemic I used Ava in the grocery store to communicate because everybody was wearing masks. I could turn my phone around and Ava rotated and the microphone goes behind my head so I can't take this off. These are the microphones on the top. My grocery store they must know by now I have hearing loss, right? So I would say to the grocery clerk -- oh, we have to wear face masks and I can't understand what you said but I have this really cool thing on my phone. I would open up my Ava and show it to them and say can you believe that? I can read everything you can say! You know, if you didn't do something like that and you stuck your phone in somebody's face. What I wanted to do is reach my phone out so that the microphones were closer to the speaker. If you didn't do that -- someone sticks something in your face. It is really unnerving. But the way I did it I didn't have any problems. That would be the issue. Where does the minister put the phone? If you can think of a great idea about that I would love to hear about it.
Any other questions?

>>HEATHER: I have a question. How close would the phone need to be to the minister or the meeting leader or the banker that you were using Ava with? If they put it down on their desk and they are 3 feet away would it still work?

>>ANN: The chances are great today. The ability of the distance and things keep changing and get better.
For the problems with some of those things I am not really a good person to ask because everybody tells me I articulate really well. I have people in my meeting say why doesn't everybody talk like you. Ava is 100 for me. If you are a person that it is not accurate with -- maybe rather than blaming the app you might articulate better to improve the app. I have so different kinds of stands that I play with all the time. In the bank there's one that is like this and has an arm that comes up and you can put the phone up and you would see it at eye level. Theoretically could have an iPad on that stand and you wouldn't have to use your stand. That will is my dream. Every information counter in America have a speech-to-text app and ASL. Does that answer that?

>>PARTICIPANT: Yes, thank you.

>>ANN: Anybody else? Can you hold your microphone up higher?
We have about 5 minutes.

>>PARTICIPANT: Can you hear me? I am hearing impaired.

>>ANN: I took my program off of telecoil.

>>PARTICIPANT: My name is Gigi Clark and however I am aware of the -- what you pointed out earlier with the fire and -- it is a concern of mine. The only way I could shut down the end of my day and get a nice sleep I have cochlear implant on my left and a very strong hearing on my right and getting ready to have a second cochlear implant. Getting past that -- I like to joke around, and I am a creature of the night and lip-reading is 95% of my hearing. When the lights are off I shut down. How the heck am I supposed to -- I go to sleep when my device is on. It doesn't make me safe. It is a concern -- my device is not in my room like my iPhone flashing. That wouldn't wake me up in a deep sleep. People like me are in deep trouble if anything were to go off.

I do have the vibration alarm clock for my bed and even they were not super effective if I had an exhausting day. Does maybe Earnest have in I go to say with extreme loss.

>>ANN: These safety carbon monoxide and smoke detectors flash and they have -- the one I have which is this one -- the Sonic Alert it says smoke and CO_2 and has a bed shaker. There's the bed shaker.

>>PARTICIPANT: I didn't hear the bed shaker. I am so sorry. Did it work for you and shut down for you at the end of the day?

>>ANN: This is always on.

>>PARTICIPANT: The bed shaker works for you?

>>ANN: It is plugged in with and always on.

>>PARTICIPANT: I know but do you feel it all the time? The bed shaker I tried a few of them.

>>ANN: This bed shaker is a strong one. You get to try things. You could get one from John and for me I am sensitive to light at night, and my husband turns on the hallway and I wake up. The Sonic Alert it is sounds. When I vacuum my bedroom it goes alert, alert.

>>PARTICIPANT: Thank you so much. I missed that part and thank you for repeating it. You know constantly repeating.

>>ANN: You are welcome. My pleasure. Heather, are we done? One last question?

>>HEATHER: If there's not a question that means it is lunch time.
Thank you Ann.

>>CHERI: All right. Is my mic working? Anybody hear me? All right. Ann, thank you thank you so much for sharing your perspective and your knowledge with us today. With this information I am confident that we can in fact make hearing technology our friend. Thank you very much.

(APPLAUSE).

>>CHERI: So, this next slide shows different demo situations that you'll find to my left. This is an excellent opportunity to talk to people who use assistive technologies. In fact, we actually have one of the demos for the fire alert that will be demonstrated over here as well. So we have lots of demos over here to the left. Be sure to talk to our guest from the SeaTac airport accessibility team that let them know what your experience is as you travel through the airport and they are here to share great information about the sunflower lanyard and accessibility tools you can use at SeaTac to make your experience better.

And we also have our audiologists Alexandra and Chase, and I wanted to mention Heidi, Michael, and Carolyn are here to answer questions that you might have for apps and if they don't have the answer we will try our best to find the answer for you.

Moving onto lunch we are going to release lunch to keep the line moving. If you requested a gluten-free or vegetarian meal, please go first. That is where we are having lunch. If you have a Vegan, gluten-free, vegetarian lunch you can get started and please go first. We want to make sure everyone who has special needs and has a special box lunch -- grab your lunch. Then you

can check the tech out here on the left. We have 5 product demo tables. Those of you who are omnivores we will let you go in just a moment. You can go through the line. Looks like we have a lot of omnivores here.
Then we will begin the afternoon session at 1 o'clock. Thank you very much.

(LUNCH)

>>HEATHER: Thanks everyone. We are starting in just a few minutes. Come back to your table and we will get started. Thanks very much.

>> CHERI: Welcome back everyone. Welcome back. We will be starting now.
Okay I hope y'all enjoyed your lunch. And the product demonstrations as well. If you needed help with your Smartphone hearing apps I hope you feel more empowered. If you didn't get help I want to make sure that you do and make sure you see Heidi, or Michael or Carolyn before you leave so we can be sure to help you out.
Before I introduce our next speaker -- I just want to say that this slide was his idea. (Laughing) we think Greg is wonderful. Greg is a fire chief and -- he is a wonderful hearing loss advocate and a valuable member of the HLAA-WA community. Please welcome Greg Bawden to talk about the importance of advocating for yourself.

GREG BAWDEN: SPEAK UP! ASKING FOR WHAT YOU NEED

>>GREG: Thank you Cheri I have two hearing devices and glasses and a microphone something is going to fall off and break.
Why that introduction? I was on an elected school board for a long time. They did a lot of work in racial justice and equity really good work. At some point they asked all of the board members to tell them how they identify. I said identify as old correct deaf, and cranky but there was not a box for that.

So, we will talk about common situations that people like us can find frustrating, challenging, embarrassing, and want to talk about some solutions.
I am less interested in the technical nuts and bolts, and Ann took us through wonderful tools. I want to talk about how to ask for help and the process of inspiring to advocate for yourself.
And my technology up here --. If you follow Greg's 12 step program you'll be as happy as that guy.

Doctor's offices -- maybe this has happened to you.
There's the big plastic barricade -- the masks are on -- and they ask you a question. It might be something really really vital to your care like what is your grandmother's name is it still Morka or do you visit Patagonia? What do they usually do? They ask the same question again and they ask the question again and then they might try to say it louder. As you probably know that doesn't really help. It just makes it more distorted. I'll show you my solution in a minute. How many have had that experience where you tried checking in at a doctor's office? I figured as much.

About me. I started to lose my hearing and started wearing hearing aids about 20 years ago. I had left a career in environmental engineering to become a firefighter. And you are not supposed to be hard of hearing to be a firefighter even though being a firefighter causes you to

lose your hearing. This was a concern. One thing I did was join the hearing loss association. I learned so much that my audiologist never mentioned and we met the first meeting and I went onto be on the hearing loss association board.
In 2013 they said I would be fired. We ended up that I got to take a new role at the fire department and 15 years later I am emergency manager and got my first cochlear implant last Fall. I love outlook door adventures, travel, volunteer, teach classes, I spend a lot of time for being an advocate for our needs in the hearing loss world. I like to mention the part about all of my extra-curricular activities. My first audiologist said I don't have many patients like you who are active. They just want to go to TV and go to church. I don't have problems with either of those but frustrated that she had no tolerance for somebody who wanted to be in a noisy work environment and be active. I found a new audiologist quickly.

So, what do I mean by self-advocacy? There's a couple of key points I want to make. First off, choose the issue. Not every battle is worth the fight. So, being treated fairly and having good communication with your medical team is essential. Having strong communication and clarity talking to a grocery store clerk, maybe less so. Identify a desired outcome. To the doctor I want to be able to communicate clearly with them, so I have an understanding of what is required for my care, and they understand what my concerns are -- that is the desired outcome. Consider you have a solution in mind. It is as simple as can you face me when you are talking? That is a desired outcome.

I like to suggest that as my advocacy. It is more complicated to train your staff to be kind and polite with people who are different. Part of a regional board for King County emergency managers and they had 50 people in a room a third of this size for a meeting and broken up into separate discussions. Can you imagine the oral cacophony? I thought just no, don't go to that meeting but I had an obligation to my agency. I suggested to them use assisted listening and move the breakout groups to another room or out on the porch. It took time but I think I heard better than anybody else in that meeting by advocating for my needs.

It can be a slow and long process. In many situations I described you are entitled by law to assistance and accommodations. I urge you to do this for yourself. Also urge you to do it for the people who don't ask and I'll give you concrete examples in a bit. Help yourself/help others. If you don't make your needs met, who will?

So, going back to doctor's offices -- why is the check-in desk in a hallway with hard floors and other check-in desks in the same proximity? There's loud noise and a ventilator and I discovered at a cardiologist clinic has a white noise machine at the check-in desk. It is intentionally noisy. So the people sitting nearby can't hear what is said at the desk. They made it hard for us to hear. When you go to check in, are they facing you? No, they are facing the computer. Those are the challenges we face every day. I'll show you my solution. I printed this note. My name is Greg Bawden, and I have an appointment today. Please understand that I have a significant hearing loss and will have trouble hearing. I will not be able to hear the medical assistant call me unless they are within a few feet of me. Yelling does not help. I give them this note. As you noticed, if can speak clearly and audibly they assume you can hear audibly. I give them this note. What is your name? Is what they said. It is on the note.

This explains what I need. I see a huge improvement. They might write down the question or had people type it on the phone or show me or gesture and it is a universal sign they want my ID or driver's license. I've had a lot of success with that. The next step in the process is not as successful.

The waiting room. Great big space and a door over there to one wing and another door to a treatment area and over there is a door. Someone I call the Gopher. Stick their head out and they say -- are you calling me? Yes! I can't tell -- I called your name. Hence my try of giving them a note that I'll not be able to hear them call my name.
I've had a lot of disappointments with this. Will ask the assistant who came to retrieve me, tell you I am deaf? No. It seems so easy, but we still got in trouble with that one.

My solution still is -- I share the note and ask where will they be calling my name? Which door should I sit near? I will sit right by that. I try to make it easy for them but make it clear what they need to do for me.

So, doctor's offices. We are entitled legally to help and obtain medical care. Captions, assistive listening, I've had for 6 months as I went through a cardiac repair, they had someone typing captions for me. Then 1 day they stopped doing that.
I can see this some an awkwardness to this. The well, I had this embarrassing rash, it might be awkward in front of the interpreter. I've had screens wheeled in with interpretation with sign language or captions and there's someone off site listening. So I am deaf and need captions or assistive listening systems or some other tool and ask again when you get there.

These pictures are just stock Internet pictures. Notice something amusing. Not one photo -- and a did a Google search for doctor or Zoom room had a picture of a computer screen. It looks like a patient, doctor, and computer screen. The modern record keeping they are typing and looking at this. I went through cardiac surgery and there's a long list of medications and they were saying are you on -- blah, blah, blah medication. And they turned the screen are you on this one? This one? It made the process easier for them and me.

New venue. Theater and live plays, movies, distance from the stage, accents and sound effects. How many understand the words in those situations? I thought that would be the case. What options are available to us? So, again I am not going to go into all the details of the types. We will talk quickly. Assistive listening systems whether FM or infrared and hold the receiver or listen might be captions. Some have live captions and a special purchase. I took my little girls they are in their 30s and they had a live captioned event. Dad. That was so amazing and I had no idea what they were saying. They found it beneficial. How many people have used the caption glasses? Talking to the people at the theater they are used regularly. There's a signup sheet yesterday and yesterday and day before and day before. Assistive listening systems in a theater are very rarely do they get used. That's what I want to talk to you about.

If no one ever did, how much longer are they going to support them, provide them, make sure the batteries are charged? So I try to ask for my benefit and asking for the benefit of you and anybody who comes after us. If nobody asks to use those they won't provide them.

One more piece I want to mention about assistive listening systems. I've been to facilities and there's a wonderful museum that has live animal presentations. They did not have assistive listening, and I mentioned my frustration and then offered my help. Do you need help choosing and testing one? I am the best friend when it comes to assistive listening. They bought equipment and invited me to come through, and I got free admission and tested it out. That was my offering a solution to them.

Airports. Raise your hands if going through TSA makes you nervous. I am afraid of getting things wrong and being deported to Oregon or something.

There's a long line of people and there's the background noise -- there's no written directions. I am in line, shoes on or off, cell phones on or off -- there's no signs. I asked TSA and no, they don't do that. They like to have someone with a badge walk up and down the line and shout instructions. I have no idea what they are saying. There's tips and tricks to get through TSA. This is a program called TSA cares. You can get this card and download it at TSA.GOV and fill in the detail of your auditory challenge or disability and it has phone numbers and contact information. It is something you can show them, and they will know that you identify as d/Deaf and hard of hearing. You can call which I find very challenging and request assistance and schedule someone to meet you and walk you through the process. That is two options. Present the card or call ahead. You still go through the complete screening process it is not a free pass. It is a way to identify you and recognize --.

Did you talk to SeaTac airport and talk about sunflower lanyards? It is another way to make your needs known by advocating for yourself and voluntary and a visible indicator that you have a need or challenge that is not available.

Airport waiting areas. This is a favorite of mine. Airports might be noisy. They have the garbles overhead announcements. The people who make those announcements did all of the apparent voices on the Charlie Brown -- and there's no scrolling or caption.
There's so many announcements. You are at a gate and announcements for that gate and something bad is happening about gate B 3 and something is going on and on and how do you make sense of all of that noise. You can get Alaska or Delta's apps that alert you. I fly Alaska and check a box when I buy a ticket and identify as Deaf. I can show the gate agent or the cabin crew. You can pre-board as someone with a disability. I went up to the counter once and said do you have any kind of video screen when schedule L board the flight. They say oh, pre-board. Save you that stress am I in the right group or not? That is how you can make your needs known and you can get as a result.

I'll talk about one more category of self-advocacy.
Your audiologist. I had an audiologist who dismissed my needs because I was too active. I found a new audiologist. If you have an option insurance plan find one who can meet your needs.

Next -- maybe this is a parent/child thing, but my mom and mother-in-law have hearing aids but refuse to wear them. I would consider myself an expert and advise what they need to do but they don't know it. How many people you know don't wear their hearing aids but have a buzzing sound or not secure? Most audiologists will strife to fix those problems for you if you just tell them and ask for help. I cannot emphasize that enough. Every audiologist I've worked with has been truly committed to doing a good job and solving challenges, but you have to tell them. That is another example of advocacy.

So, think about what works for you. What works for your friends? Let your needs be known. Do it for you -- do it for other people in the same situation. Do it for the people who come after us. I think I have a couple more random notes here.

I just can't say enough about the value of speaking up and making what you need clear. People say arguing about these issues is like wrestling with a pig. You are not going to win. It turns out that the pig likes it. I love to argue these issues. I make no effort to hide my needs and that is why I have a flashy blue cochlear implant. There's a picture of me skiing and there's a label on my helmet that says I can't hear you. Don't be shy and let your needs known. I believe we have time for questions. Once again, microphone!

I see a question here and over here. Front row --

>>PARTICIPANT: You talked about movie theaters. I thought it was either caption glasses or assistive listening devices, but you recommend asking for both?

>>GREG: I was lumping movie theaters with other theaters. Have you seen one where you hold like a mirror and the captions are on the back wall? Live theater are not equivalent. One of our most popular theater the microphone is hanging over the stage. I was pleased to have my FM, and I was hearing everybody in the audience cough and it was not a mic.

>>PARTICIPANT: I have another question. You talked about presenting yourself as deaf, so you find that works better than saying you have a hearing loss.

>>GREG: If it is a conversation I say late deafened. Without the cochlear implant I hear nothing. It causes confusion because there are people who are Deaf and I find that people say they are hard of hearing. Yeah I went to too many concerts too. Nothing I did contributed to this. That is one of the challenges I found. Okay?

>>PARTICIPANT: Hello everyone. Speaking of the airport here. Many deaf people do check in and go through and let them know that they are deaf and they go into the airplane and.

(CAPTIONING STOPPED HERE).
(A BRIEF BREAK WAS TAKEN)

>> HEATHER: Okay folks thank you. We are up and running. So, we are going to show -- Cheri do you want to speak first?

>>CHERI: I want to talk about live movie theater and live theater. In the movie you receive an assistive device and neck loop, and you can you go also request the caption system which we saw the two photos.

Most people don't request both systems because you leave the hearing and how do you carry the popcorn and Coke into the theaters? You find hard to minimize that so we have open caption movies. You have to use the caption glasses I wanted to remind everyone with the Washington State association for the deaf and Senior Lobby and HLAA-WA we want to get it so there's more captioned movies in movie theaters. We want to let people know we are using these systems and making the difference for us showing up and being a paid attendee or not showing up at all. There's lots of options. I am just going to say -- do you have a quick thing?

>>PARTICIPANT: I wanted to comment that the theater on lower Queen Anne has open captioned movies on Tuesdays and they are only $7.

>>PARTICIPANT: This follows up on previous discussions on airports and have to do with transportation. We have bus lines and trains going up to Everett and going to Tacoma. Can you talk about the hearing on transit? Because we are trying to get people out of cars? We want to get them to the airport and all of that. You have a background you know something about the importance of broadband and reaching the capacity for people using their little phones to communicate with hearing loss. Any comments about that? That is too much --

>>GREG: Those are a bunch of good questions and don't know if I have time to get to all.

If you didn't get a chance to talk to the folks from SeaTac about the sunflower land yards they are reaching out to Sound Transit. They are working on these different transportation modes sharing this approach and that is a way to identify your needs. That is not the be-al end-all. I've been testing the Washington State ferry system for 15 years and they reached out to me the director, to give me an update to make transportation more accessible. There's a lot going on. Broadband, I understand how we rely on those tools. I don't have expertise on what is going on there. Right up front you asked about the airport and bringing you a wheelchair. That was right when I broke the captions. I would just continue to articulate what you do need and what you don't need. If you all make that effort we might win.
We are just about out of time.

>>CHERI: I would like to turn the mic over to Candace who is ADA for the airport and will talk about what they do have for us.

>>CANDACE: My name is Candace and you'll see my name -- feedback? The door and water fountain at the airport and how to complain to me.

Oh, okay. It is very bright. Okay. Didn't plan this.
So, nondiscrimination based on disability is very important and we would like to know what is happening and fix those trends. Something I hear all of the time from deaf, hard of hearing passengers and blind the ones who have guide dogs are met with a wheelchair. You need to advocate for yourself. I booked a specific type of service, and I expect that and I do not need a wheelchair. Sometimes there's turn over with those roles and what you can do is ask for a manager.

Any time before your travel during or after your travel you can speak to a CRO which is a Complaint Resolution Official and every airline is required to have one onsite to meet with you in person or on the phone when operating flights at any airport in the US. That person will make sure your situation is resolved and there is -- if you say I don't need the wheelchair and they are not accepting that -- that person will fix it for you.

Please do that. Check out the FAA's the passenger Bill of Rights when it comes to disabilities. I have a printed sheet on my table if you haven't grabbed one that has a QR code that will take you to that page. There's different sections. Assistance at airports is one of those and will give you more clarity what you should ask for and don't be afraid to add it to your booking when you are booking the ticket or calling or e-mailing after you book the ticket. You can add it at the airport when you check in. Don't let anybody tell you that you don't need that or it can't be provided. It absolutely can. If you get any resistance from the airline or service providers tell the ADA coordinator at the airport and you can complain to the FAA because that stuff is documented and airlines can get in trouble when they get those type of complaints. Please let them know. Otherwise it won't get better.

>>CHERI: Thank you for reinforcing that message that it is up to us to make that ask and let everyone know what our needs are.

>>HEATHER: We will now take a 15-minute break and sorry we couldn't get to everybody's questions and Greg is still here if you have another question. In 15 minutes, we will start our panel discussion and then it is good-bye and out into the sunshine.

(A BREAK WAS TAKEN)

>>HEATHER: Thanks everyone for waiting. We have an engaging panel of the hearing loss community. Thank you all we are about to talk our panel and I'll introduce Alex Alfieri and who is our moderator.

PANEL DISCUSSION: HEARING LOSS IS A JOURNEY. HAVING COMMUNITY HELPS.

>>ALEXANDRA: And I am a clinical audiologist at Virginia Mason Franciscan Health and work in Seattle and Federal Way and been an audiologist for 2 years and president elective and trying to be invested in this community.
So, as you all may know hearing loss can be extremely isolated when it doesn't have to be. I have 4 women here from 4 different backgrounds in the HLAA community that we can all learn from.

I think we should start this discussion with what makes us great community. Jacqui, what brought you to HLAA and the initial impacts of hearing loss that you have experienced and other people have.

>>JACQUI: Hi everybody. I know that this has been a long day and it has been very intense for all of you. There's so much to learn about hearing loss. I realize that Alex asked me to talk about some of my experiences and I have lots of stories as we can all tell lots of stories.

The most important thing I began learning was back in 1987 when Sam Trychin a psychologist from Gallaudet University, did research on how to best manage hearing loss. He came to Seattle. I took a week-long workshop with him. A tthat time I was reading a lot of sign language and working with interpreters. I hemmed and hawed and said okay. There I began learning the things that I can do to make it easier to understand what is going on. I got rid of the interpreter and able to function very well at that table of people who were in this workshop because he was teaching us how to manage our hearing loss and what to ask for and how to ask for it and it made all of the difference in the world. That was in 1987. That's a long time ago. I've been working with this information and been dealing with these challenges since then. That's a long time. It takes a long time to develop a whole lot of skills at it.

So, here I am speaking in front of you. We had quite a day today. You know, I've learned that it is important are to learn about equipment. It is really important and so appreciate the information we've gotten today learning how to use our cell phones and the various equipment. It takes patience and motivation, and a lot of energy ho learn how to use what I call -- this technical stuff. There's the soft side of coping with hearing loss.
The things that we do to connect with people, the things we do to help others help us in understanding -- Greg talked about this. I want to say this specifically. The things that we can do just in our -- thank you -- I have to keep the microphone at my face. I forget. Learning how to do what you need to do takes a lot of practice. This is a good example of that.

So, when we tell meme what we need from them -- when we say to somebody hey, I am hard of hearing, and they look at you and you see this blank look. We need to tell them what we need them to do to help us. Speak slower and louder. This is so important. Something to think about how we tell people what we need.

Again, how many of you here have had a hearing loss for a long time? Look around. Look around. How many of you is your hearing loss more recent?

Fewer. There's challenges each way. For those of you who have had pretty good hearing most of your life it is hard to figure out how to manage with hearing loss. Those of you with hearing loss for a long time it is hard to remember what you need to do and learn new tricks and get rid of the old ones and learn new tricks. We are challenged by our hearing loss.

>>ALEXANDRA: What I am hearing from you is other people involved and providing support for you. Kimberly can you talk about accessing support either in yourself or the HLAA community.

>>KIMBERLY: Yeah I can do that. I really want to just share my own experience. Some of you know that I am with HOPE on line support group for people with hearing loss and supported by HLAA-WA and there's several of us in this room who are facilitators. It is free and we meet on the first Wednesday of each month. We offer support with one another and sometimes we have speakers and audiologists and other people talking about having a hearing -- we have been meeting for over 5 years now and it is well received. A national program and learn so much from each other. I wanted to share my own experience about my past with hearing loss. I grew up with untreated hearing loss and started -- diagnosed when I was 8 and my family denied that diagnosis and I struggled through school. I got my first hearing aids at 22 and put them in a drawer and no one taught me how to manage my hearing loss. I had a lot of shame about wearing hearing aids.

So, I struggled for many years. When that happened -- the isolation and depression, the shame, with all of the loneliness and things we experience with untreated hearing loss. I had a child at 28 and wanted to be able to hear him. I went and got hearing aids and I wore them full-time and they made a difference. Then I had another child and I continued to lose more hearing because I had a progressive hearing loss. I became deaf in my early 40s and luckily I found the HLAA and that is being a member. I walked into the first meeting and didn't know anything about a hearing loss and I thought I was going to hear in that meeting and I sat and cried for the first time I felt like I was a part of something and I could understand and then I went to my first HLAA convention.

It was amazing because there was captions everywhere and FM systems and all of you sudden a world of communication opened up for me. Then I started meeting people and I got back and became a member of Washington State and then I went to Gallaudet and became a peer member, and I wanted to have a better quality of life and empowered and have a big quality of life and I wanted to help others. I was on the board for 3 years and helped a lot putting together programs and MC-ing events and then when the pandemic happened in 2020 I became very depressed. I was isolated and fearful, and the masks came out and I was deaf again. I didn't realize how much I depended on speechreading. I was afraid, depressed and isolated. I had to have my husband go with me for simple things I used to go on my own even to the grocery store to interpret. Cheri called me and said I heard about these HOPE meetings throughout the country, and you would be good facilitating would you consider? I said I'll get back to you, and I went to different HOPE meetings around the country and started taking notes and curating a vision I saw for our Washington State chapter to be a national support group. I started inviting people in this community to be facilitators for that. I got back to her and said yes, I'll do it. It was because I needed to get out of that hole and depression. I needed to get back into the world. I needed a purpose to do that. My purpose was this organization that had given me my life back. So, I will always serve HLAA one way or another and it is time for me to wrap up.

>>ALEXANDRA: (patted Kimberly on the shoulder) I was trying to be supportive.

>>KIMBERLY: I can't stress the importance of knowing people with hearing loss having friends with hearing loss. People don't understand what it's like because nobody else understands. Please come to our HOPE support meetings.

We have graduate students to come to find out what we are all about. We have wives who come whose husbands are in denial. It is an amazing community. We advocate for each other and cheer each other on. I cannot imagine going through this journey alone because I know -- I did -- I did it for so long. I was able to contribute and give back and it enriched my life. This is my happy place with my hearing loss family. I encourage you to learn everything you can about your hearing loss because it will change your loss and improve the quality of your life.

Absolutely have friends who have hearing loss. They will support you and they will go to the ends of the earth to help you because they know what it is like and how hard it is and want to make your journey easier. I talked enough.
Anyway -- yeah. I hope you'll join us and volunteer and get involved and -- you'll learn a lot and you'll make great friends. Thanks.

>>ALEXANDRA: Everything you shared and Jacqui wants to share more.

>>JACQUI: I want to talk about the emotional hearing loss. We heard out here today and all of you recognize these feelings and isolation and sometimes depression and feeling cutoff. It is joining this kind of a group and becoming friends of people and learning about other people who have hearing loss. This is the beauty of this group and this community.
Yes. Cheers!

(APPLAUSE).

>>ALEXANDRA: There's many different avenues and niches under of HLAA-WA and the HOPE meetings for you and other people may have different interests. Heidi do you want to talk about your experience and volunteering for HLAA?

>>HEIDI: For me HLAA puts me with other people who also have hearing loss. In my case I lost my hearing about 5 due to unmanaged ear infection and denied hearing aids until age 15 and I got one. I didn't know anyone who had a hearing loss. At 15 my mother ran into a long time HLAA board member -- this is really emotional. Because I ran no Carolyn Odio and she talked to me and I volunteered her time to share with me best practices and introduced me to the community of people with hearing losses. I should not be 51 years old and find out I like people. Now that I found best practices I got an audiologist that follows best practices. I went all in with technology with hearing aids programmed correctly and how to use my app and such as Bluetooth and Rogers and now I am totally in love with Auer cast. The and volunteering means you have all of the answers. You have the passion to share everything that works for me may not work for you. It is a place to start to get more questions and have more options.
And the better thing is the more you volunteer and get involved the more you can hang out with other people who have hearing loss. We all know a little piece, and we can share that with other people.

(APPLAUSE)

>>ALEXANDRA: Thank you for being vulnerable. I understand it is not always easy to talk about. When we do it makes us closer being vulnerable.
With numbers in terms of advocacy and peer support -- everything.

As an audiologist I know that I can do let's say X amount. I am not doing 100% of what everyone needs. There's opportunity for a support system that you can't always get in the doctor's office.

As I am talking about advocacy and sharing about numbers I'll learn toward the HLAA-WA president who has a lot of experience. I have personally had a little but it is daunting. Do you mind sharing your personal growth in this and what you accomplished because I know it is a lot.

>>CHERI: Thank you. I just wanted to say in listening to my colleagues here I think we learned something that access changes everything.
Access to a hearing aid is really the first step. Access to a hearing aid and a supportive audiologist hearing health care professional who listens to you and understand your needs and empathizes with your situation. Someone you can go in and pour your heart out to really because it is an emotional journey. You kind of need that audiologist to be there for you.

But you know -- um, I learned from HLAA early on when myself was hard of hearing in the early 90s. I found out about the telecoil in my hearing aid and how I can use that on the telephone to understand in a telephone booth. Oh, my gosh that really changed my life.
We use HLAA other than reading magazines and the experiences of other people. That is where I got my support.

But I had a life-altering experience when I went to the UK and I was standing at a train station and I just happened to be able to hear the thick Irish brogue of a ticket agent, and I was able to understand what he was telling my friends before. I looked over and I saw what I call the magic sign, and it was the hearing loop symbol that said switch hearing aid to telecoil. I already had my hearing aid on the telecoil position because I was using it to block out the background noise. I turned the other one over and I could hear and understand him clear as a bell. I walked away looking at the sign thinking gosh, okay. That was life-altering -- I get on the train and saw the same sign. I was able to use my telecoil program to understand where the next stop was. I went on a double Decker tour bus and saw the symbol. I went straight to Dublin, and I am sitting in the back of the bus and I am able to tell them what we were doing. Everyone is usually telling me what is going on.

So, I thought why don't we have this in the United States? Why don't we have that accepts hearing loss and successful for people like me. Then I was at my HLAA convention and Kimberly was there and we didn't know each other at the time. We had hearing loop campaign and said oh, you have to do something. That is when I came back to Seattle and said I am going to start the hearing loop campaign in Seattle. That is when I started talking to other organizations and telling my story. City of Seattle was very responsive, and we learned how the systems worked and getting hearing access in city hall and different places like this. We started talking to arts organizations and this is great but how are we going to pay for it? So I found arts culture in Seattle, and they would fund the accessibility and disability. We started convincing people like Town Hall Seattle was an early one.

And the Paramount about accessibility. At some point we with the dementia and with the public speaking part and it comes out that the Washington State discontinued the Medicaid assistance program for people Medicaid beneficiaries to get a hearing aid. People couldn't leave this. They started researching this and found out it was true. Some people were really on bored to get that back to us. We were working with the Washington State senior lobby and AARP and older adult organizations we were able to do that. It took 2 years or 3 years to get that done. So the thing is if you don't first succeed try try again.

Legislation is a long game, and it takes all of us telling our story. I look at the faces here and I know there are people that I wrote e-mails to and you need to contact your legislator. All you need to do is follow the 5 simple things you have all of the tools you need in your hand and tell the story and let your legislators know. We have a challenge in front of us. We are facing lack of communication access in health care, lack in our senior and adult family homes. If you can't actively engage and participate your health is going to decline.
We have the voices right here in this room to really make a difference. That is really how I got involved in advocacy.

(APPLAUSE).

>>JACQUI: And what Cheri is saying is so important to realize the incredible amount of work that you have done single handedly with lots of support over so many years. I mean, she is amazing. You are incredible what you've accomplished and the efforts you made and much appreciated.

>>CHERI: Thank you! Thank you. I couldn't do it without a community. We learn so much from each other. I just want to speak -- we have these communication tip cards, but when you see someone and I go to a restaurant with Kimberly and go to the front desk we would really like a quiet table away from the kitchen. Then the waitress does something about that and takes it over. It is a quiet table but the radio is playing. She says we are hard of hearing and can't hear well and can you turn down the radio. I thought oh, I can do that too. So, we learn so much from each other. I just want to say that we couldn't do these things without each other. Thank you very much for being a part of our community.

>>HEIDI: Community is so important. It is really important that we all role model what we know and are hearing. For example, my life was transformed when I got technology and now I have a microphone that I can use in social situations. I was working with the same people 15 hours a week for 20 years and showed up with this microphone and it goes to my ears and they said what's that? I said I am hard of hearing, and they said you are kidding? We thought you were stuck up and snobby because you never talked to us. That is 20 years of wasted effort, and they may have been talking to me but because I didn't know better I wasn't using the technology and they don't know I was using it now they say what's that are you recording me? I am listening. Every single person without fail will say myself, my husband, my wife, my dog, somebody in their family can't hear and results in the best conversation about hearing loss. I can't tell you how many people because of a chance meeting of me modeling good use of technology has resulted in them getting hearing aids. The and getting connected to the world.

(APPLAUSE).

>>KIMBERLY: I would like to say something that just came up. I hid my hearing loss for a long time because I was ashamed, afraid to disclose it in job interviews because I was afraid I would be discriminated against because I experienced that. The ridicule that Ann was talking about earlier. And I also I was reflecting on this day and what I was going to say -- I blamed myself for so long for having hearing loss something that is no fault of my own. I was born with progressive hearing loss and got worse and worse. I now have bilateral cochlear implants. I wanted to say that. Things really changed when I disclosed my hearing loss.

People thought I was stuck up and rude and disinterested in, stupid and I got tired of people making assumptions of me. We go through the 5 stages of grief, denial, anger, bargaining, I can't remember -- it comes to acceptance. When I could accept my hearing loss and more importantly I was ready to do something about it so I could have a better quality of life. Things

really changed. When I began disclosing then people were like oh, I was wondering what was wrong? Is that all? You just have a hearing loss? I thought you were really stuck up. I got comfortable disclosing and then comfortable advocating for myself. That was the only way to get along in the world. I had to do it. I get tired sometimes. My HOPE -- our HOPE meetings are so powerful. I learn something every time I learn. We have 25 people come regularly. There's like 100 years the experience of people with hearing loss that can share their experience and give us hope.

So, then it got easier and I didn't have to work so hard, and I didn't have to hide. People would advocate for me, and my husband can say I've had a hard time and would you please do that and he will do that. Support people. Core support people. It is exhausting to have hearing loss. It got easier when I learned how to advocate for myself and ask for help. The other thing I learned is most people are really willing to help and the people that aren't are not worth my time. I don't waste time with that. It is okay to take breaks. I've taken two breaks in the quiet room. I am glad that you opened for that. It gave us permission to take a break. Nothing wrong with that. It gives me the energy to come back into the fold and get through the rest of the day. That is all I wanted to share.

>>JACQUI: One thing I've been thinking about listening to everybody -- there are folks here who have had hearing loss experience recently where their hearing loss is fairly new. You may be older and experience hearing loss. That is a very different experience for folks who have had it for a long time. I hope that some are talking about is helpful we need people around us and information and need to use technology. It is a different experience when you are older and dealing with lots of different losses as us older people know to deal with hearing loss is really a challenge. This community can be so incredibly helpful.

>>HEIDI: One thing that is powerful losing your hearing later in life or being a part of the retirement community, you have an audience of people who want to be hearing empowered and share the experience of tips and tricks. You are more powerful together whether sharing your personal story one-on-one and Jacqui is forming a group in her retirement community.

>>JACQUI: I am not in a retirement home community.

>>HEIDI: Working with -- working with a retirement community. The more you can share about hearing and start a group to work together the more leverage you have to influence your environment to include hearing loops or Innocast is coming and to ask questions.
We will take on the world and get everything hearing enabled.

>>ALEXANDRA: Sharing is extremely important with each other and coming from an audiologist please share with us. If you share and you don't feel acknowledged switch providers. You have to do what you have to do. I am a provider. Feel free and have the confidence to do that. You deserve to be treated the way you want to. Share with legislators. I went to Washington DC to lobby for hearing health care. They don't know anything. I am going to be really honest. Your personal stories matter more than what we say sometimes. Everyone's important in getting things going for the hearing loss community. That is what I'll end with. I want to have time for questions and answers.

Anyone has a question I believe.

>>PARTICIPANT: I would like Cheri to list the legislation that has been passed regarding hearing loss since she took leadership in the hearing loss association. Many many years and it is very difficult and just as many as you can think of Cheri.

>>CHERI: That starts with you Diana and our first piece of legislation we passed which goes back to requiring Medicaid to cover hearing aids for people who are Medicaid beneficiaries. The next piece we got passed a long time was consumer education Bill. It was called the telecoil Bluetooth Bill. We had a lot of difficulty passing that bill because people did not understand it was consumer education. Here we are and we have ADA requirements that wherever there's a PA used or amplification used in a public space they are required to have assistive listening system. So we are doing that. The way the hearing assistive listening system works is for us to be able to use our hearing aids they need to be hearing aid compatible. So we would use neck loops. Well, without hearing aids they have to have Telecoils in them without using headphones on top of our hearing aids. It was a hard piece to try to explain to legislators and everyone in general who were unfamiliar with the technology.

We had resistance from the professional community and felt like what we were trying to say and tell them how to serve the patient. There's always someone who doesn't want to have the bill passed. We passed the bill that was telecoil Bluetooth education. As you heard from Heidi today she talked about how important that piece of technology the Bluetooth microphone and how important it is and how it gave her life back and went to place whereas she could hear and participate. That is the telecoil Bluetooth Bill.

The next piece of legislation we did work with the Washington association for the Deaf and we passed legislation that stated that public televisions are required for captioning. When you go into a bar or restaurant if they have the audio on you should have the captioning on. That is a really important piece.

Then just last year, we passed the open caption legislation requiring more movie theaters to have more open caption movies. We are not done yet.

We found with a Medicaid Bill we got passed -- you you don't always get to write the bill that you would like to write it. That is what an educational piece that we have learned along the way. So, we would have liked to have had two hearing aids covered. You have 2 years most of us hear out of two ears we need two hearing aids. In order to get the bill passed we were only to reinstate in 2008 when they took the bill and benefit away.

Now you can get two hearing aids today, but you have to jump through hoop toss do so. It is still something that we are working on. Of course nationally Medicare does not cover hearing aids. So the largest population of folks who have hearing loss are older. Many of us are on fixed incomes and makes it harder to spend money on something they are not sure they even need. There's still a lot more to do. The ADA has been around since 1990. How many places have you seen the hearing loop? How many places do you see captions or walk in and see ASL interpreters automatically? We have a lot of work to do and need your help. Thanks Diane.

>>ALEXANDRA: Any other questions?

>>HEATHER: Just before the open caption movie legislation that went into effect this January, we pulled together a consortia community groups and state organizations, and we got more insurance coverage for private insurers who have to cover hearing aids and hearing health for their employees. As an example. It is a good example what Cheri was saying we cannot always write the law that we want. We thought every private insurer; there are a large

percentage of private insurers that self-insure. They cover their employees' insurance through a 3rd party. They were exempt because of lobbyists who worked against the Bill. That is the next big push to get more private insurance companies covering hearing aids for their employees and their families.

>>CHERI: The reason it didn't pass the self-funded companies like the large corporations that is a federal law that has to be changed that prevents states from changing insurance location.

>>WALT BOWEN: I want to follow up on all of this good discussion. I work with many of these laws that Cheri was talking about and a few others. One of the things we know for a fact and talking about it today is that no law is self-executing it. We can make a law, and it becomes a policy and the people who adapted it at the time yeah that's a good idea, but they listen to lots of good ideas and they run off and do lots of other things. When a law gets passed it gives us the authority to cite that as policy.

Unless you said between Tukwila and Spokane there's no speed limit and that's the law. Well, that would self-execute and not many places that are self-executing. We have to advocate and education and continue. The law gives us the authority. The easiest example is the television deal. That passed and people go to bars and at the time it passed okay we have to do it, but staff changed and new staff and they don't get the word. How does that law work? We have to remind them. There's a law. Did you know that? It would be convenient to help us. You have to help to make the law work. Part of the education of that law is our self-advocacy. Our advocacy for the laws depends on our technique and skills and energy of self-advocacy. I keep advocating and with you and let me know what you want to fight for and I'll get other people.

>>HEATHER: I have one more question.

>>PARTICIPANT: Hi. One of the areas that I feel inspired from being here today to focus on and I am wondering if there are other people here and happening. The whole senior living community. It is a place when people come to see a community, they see furniture that is lovely and cleaning and they get good food but nothing in terms of hearing. Nothing! In some of the very best places. Very few. I am in a low-income place that we are kind of working with and Jacqui is helping us. I am really interested in reaching out to the high-end places that have the money to do it that can give more to people that are there and it doesn't cost us anything. It also doesn't mean legislation, you know? It is them being aware. Is that being done? Anyone else interested because I would really like to do that.

>>CHERI: You are absolutely right. When I started the get into hearing loop here, we were contacted by senior living facilities right away. Some of them were very much aware there was a problem whereas others weren't. It didn't necessarily matter if it was a high-end facility or more moderate reasonable facility. The interesting thing is -- I made a list of facilities that had hearing loops and probably 12 of them at the time. I started calling them all because I wanted to find out if that information was accurate and put a list together that we could advise people. What we found almost no one that answered the phone knew anything about the assistive listening system. I went to do a presentation, and they said we don't have anything -- there would only be a small group and maybe we can all hear each other. I was going to be in the area, and I agreed and there was a hearing loop system right on the counter. It was great news, but nobody knew it was there. Signage is required. The biggest key is staff training. We can get by with a lot even without technology and we have staff who understand there's a problem and they are empathetic and work with us on communication strategies that will work. Those communication strategies are equally important as the technology piece. It doesn't matter if we have all technology in place and no one knows how to use it. The key here with the assistive

technology is that everything workS through the microphone. I wanted to say we are trying to -- this is a big program to us to reach out to senior centers. We are limited in our capacity by a small group of volunteers. I think Julie has some ideas how we might be able to adds our volunteer coordinator. We don't have enough people to do these presentations and walk through bringing the staff on board. What we found this kind of leadership starts from the top down. You have to have the CEO invested in this. They have to be able to model that behavior and model those techniques and really ask their staff to do it. If they are not asking the staff to do it and the staff are encouraging each other -- then it doesn't go anywhere. That is one of our challenges is that.

>>PARTICIPANT: I would like to be a part of it.

>>PARTICIPANT: If I could say one thing staff turnover. What you said about leadership needed to be on board and having it be a commitment, if you look at Carolyn's facility Panorama city and they are at the highest level of serving people with hearing loss. It is good to do presentations they are needed and making sure that people who make decisions are included and are in charge of the budget and part of that discussion.

>>ALEXANDRA: Do we have time for one more question? Did you have your hand up?

>> GIGI CLARK:: This is going to go sideways a little bit. I haven't seen any (Inaudible) don't mess with the people I have to lean on my husband to help me with the right word or I might say the wrong thing. I am a cancer survivor in the peak of COVID and couldn't take care of my advocate and rely on other people to get through. I got a letter from the hospital saying I was an uncooperative patient. You are kidding me. That's that. I had a captioner to let me know what my doctors were saying.

They refused to give me the -- I am from California originally and I've been up here ever since. They cannot provide me the notes. I can't remember what HIPAA stands for. I found it distracting why I can't get captioning and no idea what I -- I told my doctors and captioning people, and I have no auditory memory to take the right medication to do what and I follow everything to the letter. Medicine is not my --. I was trying to be creative with my own and raised on captioning going to school. Captioners would (Inaudible) to get ahead in class.

Can you shed any light on why real-time captioners cannot provide the notes at the end of my doctor's session? We can't do it.

>> GIGI CLARK:: What she is asking for is the transcript of the captioning session as opposed to notes the doctor always gives notes. The back and forth between her and the doctor encoded in the captioning may reveal questions or answers that aren't relayed to the notes that don't end up in the permanent record.
>> GIGI CLARK:: The notes were never documented, and they were deleted off of the system immediately after. I tried as a self-advocate and tried to get them done.
I wonder if you could shed line on this.

>>HEATHER: Thank you, Gigi.

>>CHERI: Thank is -- congratulations to you for being able to get captions for the appointment in the first place. That is a huge thing. Do you happen to know what platform your video -- were you using a video platform or just live captioning.

>> GIGI CLARK: They made the mistake of trying to get me the video.

First round they tried to get me the video version and I don't sign. I took classes but I don't communicate in sign. So, I can't use the video. Thank you very much. A social worker recommended the real time captioner. I said oh, you have captioning in Washington. Every one of my follow-up visits -- I kept running against the brick wall. I wanted transcripts and I could not get it no matter how hard I tried. Seniors who couldn't hear very well I am getting old and I've been hearing impaired and I am used to it.

>>CHERI: This is a question I haven't had before. I have questions about people not able to get captioning at all or be able to use the captioning. Will I have not had a follow-up with the transcripts. Ann, do you have any light on that?

>> Ann: No, but I am inspired and sparked to take a look at this. I know that we've all had push back saying that HIPAA prohibits all kinds of things that are not true. HIPAA is to protect information being disclosed about us without our permission.
The ADA trumps HIPAA they provide ASL interpreters for meetings and things and Cheri, I don't have more information about that. But I am intrigued.

>>CHERI: I am intrigued too.

>> Heather: I am so sorry we have to wrap up the panel and the Q&A. It is something that is a good example of the importance of volunteering with our organization because we can understand what the issues are and can figure out how to help. Reach out and volunteer if you are interested into reaching into senior homes and requirement centers and talk to Julie about volunteering. There's so many opportunities and you can wrap.

>>ALEXANDRA: Thank you for the questions and you all provided a different viewpoint for myself and audiologists. I want to thank the panel for sharing their emotional journey and not easy to share.

>>CHERI: Thank you very much and for moderating.
I'll stand up. I hope that maybe I'll move over to the podium. I hope today's perspectives on having a hearing loss community inspires you to stay connected with HLAA-WA. It is a mutual beneficial relationship. The good news is there's lots of ways to be involved. HLAA Washington is powered by you our hearing loss community.

Each one of you are essential to the work that we do. So there are several ways you can stay involved. Sign up to receive our newsletter, volunteer, visit our website, and follow us on social media. Join the monthly HOPE meeting, help raise awareness about your own hearing loss. I have hearing loss can you talk to me over here. I have hearing loss; can you speak a little slower. Ask for hearing access everywhere you go. And finally encourage your friends to get their hearing tested. Thank you today for being a part of our HLAA hearing loss community and bringing your energy and perspective to our 2026 community day. Stay in touch and have a safe trip home!