

**Participant Comments Submitted
Prior, During and After HLAA's
Externally-Led Patient-Focused
Drug Development (PFDD)
Meeting for People and
Families Living with
Sensorineural
Hearing Loss**



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Meeting Date: Tuesday, May 25, 2021
10 a.m.-3 p.m. U.S. Eastern Time (Virtual Meeting)
Document Date: September 30, 2021

This document accompanies and supports the “Voice of the Patient” report, available at hearingloss.org/programs-events/patient-focused-drug-development-meeting/.

Introduction and Context

The Hearing Loss Association of America (HLAA) held an Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD) for people and families living with sensorineural hearing loss (SNHL) on Tuesday, May 25, 2021. This EL-PFDD meeting was modeled after the work of the FDA’s Patient-Focused Drug Development (PFDD) initiative. PFDD is a systematic way of gathering patient perspectives on their condition and on available treatments. The information gathered at the meeting is presented in the “Voice of the Patient” report and will be used to guide drug and technology development and inform the FDA’s benefit-risk evaluations when reviewing technologies and therapeutics to address hearing loss.

The meeting brought together people with SNHL and their families, representatives of the FDA, government agencies and the military, as well as representatives from state agencies. Meeting attendees included representatives from industry, academia, advocacy groups and nonprofit organizations; in total, seven supporters, 56 partners and one collaborator joined the HLAA to support this meeting. An online comment submission portal was open for 30 days before and after the meeting to allow as many voices as possible to respond to the Meeting Discussion Questions. These questions were posted on the HLAA website, presented at the meeting and are included in Appendix 3 of the “Voice of the Patient” report.

Written comments submitted to the online portal are included in this document. The written comments are presented in the order that they were submitted and were edited slightly for grammar, spelling and punctuation. Respondents are identified by their first name only. Those questions not addressing the Meeting Discussion Questions were removed as were any comments that were perceived to be disrespectful to individuals, companies or organizations or comments promoting commercial products or organizations.

Selected comments from this document are also included in the “Voice of the Patient” report.

The final “Voice of the Patient” report, the meeting transcript, a recording of the meeting, as well as this document, can be found at: hearingloss.org/programs-events/patient-focused-drug-development-meeting/

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

Name	Comments Received
Lisa	<p>To Whom It May Concern:</p> <p>Alport Syndrome Foundation was proud and honored to participate as one of the many official partners of HLAA's excellent, Externally-Led PFDD meeting last month. Alport syndrome, a rare genetic kidney disease, also causes bilateral sensorineural hearing loss.</p> <p>As per the suggestion of moderator James Valentine who also served as the moderator for the Alport Syndrome Patient-Focused Drug Development Meeting (August 2018), I am writing to provide quotes about sensorineural hearing loss from Alport Syndrome patients that participated in the Alport Syndrome Patient Focused Drug Development meeting. Together, our voices can be stronger. Following are some key quotes from Alport syndrome patient participants documented in the VOP report that relate to the questions asked as part of the HLAA meeting:</p> <p>How do these symptoms impact specific activities that are important to you:</p> <p>I live in San Diego, where the beach and pools are main activities for me and my friends, so I'm constantly nervous that someone might jokingly push me in a pool or ocean with my hearing aids in; that'll be disastrous.</p> <p>I've given up understanding quiet sections in movies, instead I watch the actor's expressions, and the cinematographer's angle and the musical passages to get the gist [of] the plot details, and I ask my family questions afterwards, and I've lately given that up, too.</p> <p>Oftentimes I misunderstand someone at work and make a calculated decision; only to be told I heard incorrectly. So, I must apologize and start over...I now sit quiet in meetings when I miss sentences."</p> <p>"...I spend a lot of time at sports events and sports practice, and there's just all the jokes and all the comments and things that you don't hear that you miss and everybody's laughing."</p> <p>"I even shied away from joining the Alport Syndrome Foundation, because I thought 'I can't hear anything anyways, so what's the use of being in a big group?'"</p> <p>The technology where I work is moving more toward conference calling and all, which makes it especially difficult to hear when you don't have a face to get cues from."</p> <p>(Parent of a young son with hearing loss): If he goes swimming, he can't wear his hearing aids when he's swimming and when he goes for sleepovers and he's sleeping in</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

while the other kids are talking... He's not going to be able to do the normal things that kids do.”

What are you doing (or what is your loved one doing) to help treat hearing loss, and how well are those treatments working?

“Without an FM, which wirelessly allows my teacher's voice to go directly to my hearing aids, background noise was interfering with my ability to hear the teacher... I take the bulky FM system from class to class, so each teacher can clip on the microphone.”

“I can't carry on a conversation without putting on my devices, and that's not easy.”

“I've also been wearing hearing aids since the age of 10 years old. They help, but I still have a hard time hearing. They help me to hear the sounds coming from behind me as well as in front of me and this, of course, I need for driving.

What are the most significant downsides to those treatments?:

“I've worn hearing aids for three years now. They do help but work best if others are willing to understand and accommodate how they function. I had to bear the expense out-of-pocket. And now that I'm retired, I'm concerned about how I will cover that cost at a time when they need to be replaced. Managing my hearing loss is another continuous reminder of having Alport syndrome.”

(Parent of child with hearing aids:) “I do worry about bullying and learning disability because he can't hear the teacher.”

“But my hearing loss caused increasing difficulty for me to communicate effectively at home and at work.”

“We know so many kids who cannot afford good hearing aids, and it's such an issue in our community, and so many other kids are going without... They're seen as cosmetic by the insurance companies, rather than as a need.”

Conclusion in the Alport syndrome “Voice of the Patient” report:

- Hearing loss can be socially isolating for patients and can present difficulties at work and in school.
- Hearing aids are expensive and are often not covered by insurance, restricting their availability to many patients. Therefore, the treatment of hearing loss in AS patients represents an economic disparity in this population.

A copy of the “Voice of the Patient” report from the externally led Patient Focused Drug Development meeting on Alport Syndrome is linked here: alportsyndrome.org/about-alport-syndrome/voice-of-the-patient-report/

Zina

Submitting a statement on behalf of the HLAA Young Adults Hear group:

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

- We are Young Adults Hear (YAH), an HLAA group dedicated to addressing the needs of young adults with hearing loss. Below are our pain points as a community. We hope that any solution considers or addresses these needs.
- Health care: navigating the health care system as a young professional transitioning to the working world is challenging.
- Lack of commercial hearing aid insurance coverage disproportionately affects marginalized groups
- Affordability of assistive technologies is a huge issue, especially due to lack of insurance coverage
- Hearing aids or cochlear implants alone aren't sufficient as for noisy situations, sometimes people elect to purchase additional microphones to amplify sound which often are not covered by insurance
- Lack of training for health care professionals on how to communicate with individuals with hearing loss
- Lack of widespread use of transparent face masks
- Insufficient use of assistive technologies in health care settings
- communications are majority phone conversations when discussing sensitive medical information. Individuals with hearing loss often have difficulty hearing on the phone
- Difficulty contacting health care professionals with the assumption that patients can hear on the phone and call when issues arise (particularly important for emergency situations)
- Noise and socializing: addresses noisy environments and poor acoustics
- Impacts entering romantic relationships and finding partners with hearing loss
- Affects ability to socialize with hearing loss
- Excessive noise can damage hearing for all ages
- Contributes to stigmatization of hearing loss
- Workplace: finding jobs and transitioning to the workplace is challenging for people with hearing loss
- Success in the workplace often requires skills related to socializing and networking events in different acoustical environments.
- Accommodation requests and accessibility are rarely considered in informal events such as happy hours in a bar setting or team dinners
- First step to the interview process is often a phone screen where the recruiter calls the candidate - not accessible for individuals with difficulty hearing on the phone
- Automatic captioning in speech-to-text apps is sometimes not accurate, causing delays in understanding
- Discrimination in the application process
- Requires considering disability disclosure
- Stigma associated with getting accessibility equipment

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<ul style="list-style-type: none"> • Often, candidates with hearing loss may choose to only disclose their disability once they have received a written offer, fearing that requesting for accommodations during the interview process may put their candidacy in an undesirable light • Although illegal to discriminate, in practice it's hard to determine if discrimination occurred if a candidate is rejected from a job application • Transitions are particularly challenging, navigating a new environment and find the right resources and accommodations • School/Education • Discrimination in the application process • Barriers in interviews, standardized exams • Transitions are particularly challenging, navigating a new environment and find the right resources and accommodations • Finding a captioner who can transcribe technical material is difficult • Many people with hearing loss do not even know what accommodations exist • Socializing and connecting with classmates in freshman dorms can be difficult to hear • Intersectionality, which is how the overlapping and interdependent systems of discrimination or disadvantage of hearing loss are amplified with race, ethnicity, class and gender. • Barriers associated with hearing loss disproportionately affect underrepresented minorities (URMs) • Health care disparities are compounded when considering other URMs (e.g., race, ethnicity, gender, etc.)
Karen	<p>Most significant impact on quality of life: unable to participate in normal conversation. Next: loss of ability to enjoy music. It is distorted. Last: no TV. Voices have echo or feedback.</p>
Joe	<p>Inability to hear much language, music and nature sounds. Communication (listening) and other losses that affect the quality of my life force me to adapt to those losses and try to compensate in other areas of my life.</p>
Marcia	<ul style="list-style-type: none"> • #1 friendships, feeling of being left out, not having the joy of following along and always having to listen for key words to know what is going on • #2 I had to quit my teaching career because I wasn't sure the children were reading correctly because I could not hear their pronunciation, when I was in charge of being their teacher. Also I like to be included and when given a task not sure I am hearing correctly what is expected of me to do. • #3 I have been working hard with my audiologist and have worn expensive powerful BTE Aids for 20 years that seem to compensate for my severe loss

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<ul style="list-style-type: none"> #4 The cost of the aids not covered by insurance discourages me from buying them since new technology keeps changing. My being retired and living on a fixed income makes them unaffordable.
Carla	<p>I have bilateral sensorineural hearing loss. It is a costly challenge to provide adequate hearing devices for myself and my spouse who also has hearing loss. Hearing aids are very costly and can be very difficult to afford especially with other competing factors of life including family needs, housing and transportation needs. The idea that hearing aids have shelf life is also daunting since it seems we need to spend thousands of dollars every 5 to 7 years on hearing aids but cochlear implants are covered. Hearing aids are not the only devices needed, supplemental microphones and other hearing assistive devices are needed on top of hearing aids and can be costly as well. There should be medical insurance coverage for these devices and glasses as they are essential to providing participation in normal life activities and employment.</p>
Christy	<p>Of all the symptoms that you experience (or your loved one experiences) because of hearing loss, what are the 1-3 symptoms that have the most significant impact on quality of life? Disconnect impact on mental/emotional health, fatigue, impact on memory due to brain strain.</p> <p>How do these symptoms impact specific activities that are important to you? Thief of minute-to-minute enjoyment with family and friends -social gatherings no matter how strong communication strategies are. Organization, day to day energy loss.</p> <p>What are you doing (or what is your loved one doing) to help treat hearing loss, and how well are those treatments working? Hearing Aids (HAs), Bluetooth to phone / TV, hearing loops</p> <p>What are the most significant downsides to those treatments? HAs don't correct, but I'm still grateful for their advantage.</p>
Louis	<ul style="list-style-type: none"> Participating in group conversations Unable to enjoy live TV because captioning is so terrible. It continues to get worse over time. When watching the news for example, captioning is either "Chunking (hesitates then plays catch up so fast you can't read the captioning) or it stops before finishing what was said. People who speak so quickly my brain doesn't have time to analyze what it "Thinks" they were saying. Trying to understand what people are saying while wearing masks. Sound is muffled and I can't read their lips.
Carol	<ol style="list-style-type: none"> 1) Old fingers fumble when replacing parts on the tiny hearing aids. 2) Ear wax renders the hearing aids useless. 3) When they don't work. I can't tell why. Is it something I'm doing or not doing? And I don't know what to tell the specialist. Need better ways for them to diagnose problems.

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>4) I moved to a town which doesn't have the quality care I was accustomed to.</p> <p>5) Hearing aids are cost prohibitive. Impossible to buy new ones every few years when needed.</p>
Dave	<p>I have a moderately severe sensorineural hearing loss with persistent tinnitus noise. I am cynical about doing more to help hearing loss through more new technology. I am not against technology - I use it myself! But technology is not the only thing people need to hear better. Hearing loss people need others to be understanding and cooperative. And I would not know how to get best benefit from my hearing aids without my professional hearing specialist.</p>
Cyleste	<p>I have severe to profound bilateral sensorineural hearing loss. My main symptom is the inability to understand conversational speech 1) in a call or Zoom meeting 2) in a group situation 3) with anyone wearing a mask. My main concern is being able to perform my essential job duties so I can keep my job. I am an info systems analyst/ programmer and need to be able to communicate effectively which sometimes requires that I present and facilitate. At this point with no CI [cochlear implant] and only behind the ear (BTE) hearing aids it is a mentally painful process.</p>
Carol	<p>My hearing impacts my relationship with almost everyone. Everything takes longer if people don't look at me when they speak or [don't] speak less quickly since I believe I may have auditory processing disorder as well.</p>
Latisha	<p>2. How does hearing loss affect you on your best and on worst days? Describe your best days and worst days?</p> <p>On a worst day, is when I'm attending a number of digital platform meetings on the same day and listening fatigue sets in. I feel exhaustion and tired, my eyes get puffy, and I feel mentally drained. After a while, I will zone out and stop trying to listen, read and follow the conversation. At the same time, a worst day is when it feels that my ears need to pop and won't. The pressure in my ear causes muffled hearing and make it difficult for me to understand words. On these days, the TV doesn't seem loud enough. Anxiety increases and I think that I've lost more of my residual hearing. Another worst day is when I experience listening fatigue first thing in the morning. My husband is a talker and some mornings he talks as soon as I awaken. I find myself getting exhausted from paying attention to hear him. In addition, group conversation is exhausting especially in meetings. I still don't prefer to talk on the phone due especially if there are numbers, I need to press to reach a live person in customer service. It's exhausting talking on the phone even with captions.</p> <p>My best days with hearing loss are when I can hear the music in the car. Hear sounds I never heard in the park. For example, last month I hear a woodpecker for the first time. I was able to locate where the sound came from and saw the woodpecker. The best days are always when I hear a sound and can identify.</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

Jaime	<p><i>(Translated from Spanish)</i></p> <ol style="list-style-type: none"> 1. Tinnitus, not being able to hear in noisy places. 2. It has isolated me from people, I no longer want to work in an office, but at home. 3. I have not done anything to treat it, because I believe that the available treatments are not effective. 4. They [hearing aids] are expensive and do not provide real solutions and the cochlear implant is an invasive treatment.
Priscilla	<p>My husband's speech is slurred because of Parkinson's. He usually has to repeat everything he says because I can't make it out the first time. My friend has a voice so soft that I often can't make out what she's saying. I can't keep asking her to repeat what she said.</p> <p>With glasses and a mask, I often feared inadvertently pulling out and losing my hearing aids so that I sometimes just left them at home. Can't hearing aids have a Find my iPhone type option?</p>
Wendy	<p>To answer the first question above:</p> <p>I was diagnosed with SNHL 5 years ago. Went to 3 ENTs [Ear, Nose and Throat Specialists] to be certain. Worst symptom for me is tinnitus. It affects my ability to fall asleep and intrudes on watching tv for some reason. The hearing loss itself has me avoiding crowds, loud restaurants (which defines most these days), theaters and even family gatherings are difficult because of jarring cross conversations and playful children. I have not yet tried hearing aids, hoping my other ear would compensate. My other ear though, tends to be extremely sensitive to sounds and any loud sound is amplified for some reason.</p> <p>Also, when walking or driving, I cannot tell from which direction a noise is coming.</p> <p>That's my list. Thank you.</p>
Donna	<p>I have hearing loss and tinnitus. It makes it really hard to watch TV, talk to health care providers and store clerks, etc. I live on Social Security Disability Income (SSDI), which is only \$800 a month. I can't afford hearing aids and don't qualify for assistance with getting a hearing aid. I avoid group meetings because I can't hear and participate.</p>
Dorothy	<p>I wear a hearing aid in both ears and when I am in a doctor's office or where many people are present, it is very difficult to hear because of the background noises, air conditioners, traffic or nearby conversation. Therefore, I smile a lot!</p>
Trischanna	<p>Louder than average sound, which can be painful. Inability to hear and understand sound emanating from digital equipment. Unable to hear folks with masks.</p>
Barbara	<p>I have been totally deaf in my right ear, following a stapedectomy, at age 26. I am currently 74.</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>I have adjusted my communication skills to fake my way through social events and group gatherings. One-on-one I do fairly well. I am told my hearing in my L ear has in fact also declined. I wear a single hearing device in that ear.</p> <p>My biggest issue is with the background noise in large gatherings. I have tried the various settings to make voices heard above the multiple conversations, but find little benefit.</p> <p>Secondly, because of mono-hearing I have no idea where the sound originates from. With a group of two or more in front of me, if I do not see the person addressing me, (and I don't recognize the voice), I do not know who to respond to. This is a very embarrassing situation, and I do not socialize well because of it. I often isolate myself at events and/or do not engage in conversations.</p> <p>Lastly, I am a caregiver for my husband who has Lewy Body Dementia. I am feeling stress that I cannot hear if he needs my assistance. Also, his voice has lowered so much I can barely hear him speaking. A frustration for both of us.</p> <p>To add to all this I have Ménière's disease. My ENT has predicted even greater hearing loss.</p>
Geri	<p>Hyperacusis, Tullio's and background noise have the most significant impact on the quality of my life.</p> <p>I do not tolerate loud noises, music ... to include even singing...sports events, movies, etc. Dining out is very difficult and many times I put ear plugs in my ears. If it is a noisy environment, my tinnitus and dizziness rages for several hours afterwards.</p> <p>I am legally deaf in one ear and have cross-over hearing aids. I rarely use them as I cannot tolerate the degree of sound emanated by them. Hyperacusis is a curse.</p> <p>I have had numerous inner ear injections with gentamicin, initially had oral and inner ear steroid injections when I began this journey with sudden hearing loss in one ear. The subsequent six years have led to a diagnosis of Ménière's disease but my symptoms have been anything but the normal etiology of this disease.</p> <p>I take a daily diuretic which has not had any effect on any of my symptoms. Pretty much have to live in a quiet world now. Thankfully am retired as I would not be able to work if I were younger.</p>
Dana	<p>I have pretty much total sensorineural hearing loss in one ear with functional hearing in my other ear. I see an ENT every year and always hear the same story....no help available and nothing new in research but I read about restoring of cilia in mice and reversing hearing loss. Where can I go for help? I am 68 and afraid of losing more hearing and I am alone.</p>
Dana	<p>1. I actually have two symptoms of hearing loss that are troublesome, being deaf in one ear and 25% loss in the other, makes life extremely difficult, bilateral tinnitus that</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>waxes and wanes that interferes with the hearing I have left, and sometimes makes it difficult to sleep because there's always noise.</p> <p>2. For starters, it made my career difficult because I almost always needed to find someone with better hearing to hear fainter sounds than I could hear or to double check whether I was in fact hearing what I thought I was and it wasn't coming from my tinnitus. Non-career-wise I'm sure people have avoided me or thought I ignored them because I simply couldn't hear them. I have been dealing with social isolation because of my hearing loss and probably lost many life opportunities because of it, especially where intimate relationships are concerned.</p> <p>3. I've tried two sets of bi-cross hearing aids that seemed to work for a while then start to fail as my hearing degraded. The other trouble with the hearing aids is that because they are bi-crossed I still have trouble with sound direction and I'm sure people wonder when they call for my attention, I always look for the sound towards my good ear while the sound or their voice is coming from the other side. They must think there's something wrong with me. I've been watching commercials for more advanced hearing aids however all of them are non-bi-cross which doesn't do much for my hearing problems. I have been scouring the country looking for and trying to sign up for any hearing restoration research trial because I need my hearing restored. But, I always either forgotten about (even when I try to sign up for the study), maybe thought to be too far away, or something, too late to participate, or told to wait then forgotten about, or when I try to follow up with a program I'm told my point of contact has left. I'm so frustrated and depressed on being told 'no.' I'm (and I'm not kidding) extremely willing to travel around the world (at my own expense) just to get my hearing fixed. Researchers don't seem to understand that I'm willing to go into massive travel and medical debt just so I can hear again with both ears and say bye to tinnitus. And I don't mind being a lab rat because my hearing loss has taken so much toll on my quality of life. I've even tried Ring Stop, body positioning and lip reading. I also tried to take part in a study sponsored by the U.S. Navy for diver's ear, no help there at all, although barotrauma is how I completely loss hearing in one ear.</p> <p>4. I can't remember all the so called "natural" treatments I've tried but I can say that none of them worked, and ear drops are a joke, they didn't do anything. So, I gave up on all these products, and diet suggestions etc. that "claim to stop" tinnitus and improve hearing because THEY DON'T.</p> <p>Hope my answers are of some value.</p>
Jill	<p>I want to hear! Everything! It breaks my heart missing out on conversations, the ability to connect being almost impossible. Listening to music. Everything. It affects everything I do. I wish we had more studies and advancement for the deaf and hearing impaired. In my case it's a progressive loss and it grieves me to no end.</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

Lynne	<p>My husband wanted me to express his wish for the future. As the husband of a person with hearing loss he feels a need for a person or group where he can discuss and learn how he can deal with his difficulties and frustrations.</p> <p>I would like to have been able to see and possibly lipread the people that had questions and comments. I did set up my iPad with Otter, which helped a lot.</p>
Ella	<p>How do these symptoms impact specific activities that are important to you?</p> <p>My hearing loss severely impacts work and social event participation as well as communication within everyday necessities such as shopping and travel.</p> <p>It would be much easier if more counters had small field looping devices as is the case in Australia and Europe e.g., the checkout, bank, pharmacy, ticket office, station. Every hearing aid with a telecoil would then be able to transmit the sound directly to the hard of hearing wearer.</p> <p>I am so very frustrated that these small, low-cost devices are not everywhere in the commercial setting.</p> <p>Of course, large looped public spaces would also make sound more accessible to those who are hard of hearing and have telecoils in their aids. The U.S. is lagging incredibly far in comparison with many other countries!</p>
Brooke	<p>The lack of insurance coverage for hearing aids and cochlear implant batteries, repair and accessories is astounding. Unfortunately, some people have to live with no or horribly outdated technology (and compromised access to sound) because of the lack of adequate insurance coverage.</p>
Michael	<p>Hearing aids that could be programmed by the wearer would offer considerable advantage. It's very difficult to describe to my audiologist what I hear and what settings seem to help speech comprehension. I have more specific comments that are based on my understanding of hearing as a retired neuroscience researcher and professor at Wake Forest University Medical School. I would like to contribute to hearing aid development and treatments aimed at restoration.</p>
Michelle	<p>Fully implanted cochlear implants would be wonderful!</p>
Lawrence	<p>I find that your general practitioner doctors for the most part have not received training to understand the needs of patients with hearing loss. They don't face their patients, they sit with their backs to the patients while they read their computer screen charts. They mumble. They don't ask questions about the patient's hearing history or family history of hearing loss. They don't ask the patient to repeat things to make sure they comprehend. I could go on, but it all comes down to training and knowledge of the subject of hearing -- they know the structure of the ear, but not how it works.</p>
Tim	<p>I would love to see more development with assistive hearing devices and training in the medical and hospital setting. Goal would be for medical professionals would have the training and understanding to effectively communicate with their hearing loss patient.</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>My mother recently returned from a medical appointment and couldn't fully tell me what she was instructed. This is very risky considering it's dealing with one's health.</p>
Michael	<p>I have moderate/severe noise induced hearing loss, from which has stemmed moderate/severe tinnitus and hyperacusis.</p> <p>I have trouble with hearing aids because they amplify sound, which my hyperacusis doesn't need.</p> <p>Tinnitus Retraining Therapy only works so much, especially with loud tinnitus.</p> <p>Instead of concentrating on assistive devices, I really think the industry needs to focus on regenerative medicine and restoring damaged hair cells and damaged tissue within the cochlea and the auditory nervous system.</p> <p>Regenerative medicine would address hearing loss at the root, instead of addressing the symptoms.</p>
Sheila	<p>I have always lived in a hearing world. I have nerve damage due to measles when I was in first grade in 1958, I am now 69-1/2. I learned to lipread, and that is how I 'hear.' This last year has been awful, since I haven't been able to hear anyone. Businesses have been less than helpful with making accommodations to allow me to have questions answered. I have stopped donating blood because they refused to take off their masks and stand 6 feet away so I can hear them, or even write the answers. As my hearing gets worse, I am not sure what my options will be.</p>
Jane	<p>When asked, my hearing aid provider said that she did not have time to help much on managing my hearing environment, even though she had covered the topic during her training.</p> <p>Until this conference, I had not heard of 'aural rehabilitation!' I want this! Where do I find it?</p>
Joy	<p>Future treatments for hearing loss for me and my family would be safe for children, safe for kidneys, safe for water use, easy to use or take, would work for sounds from every angle (think about the safety of driving with hearing impairment and hearing a siren or horn behind you, hiking on trails with mountain bikers who are calling out to you that you can't hear, etc.). Ideally, there would be a way to prevent our genetic hearing loss progression so that all of our future generations wouldn't require hearing aids and/or accommodations.</p>
Sara	<p>What are we doing to improve hearing loss treatment equity? What can we do to help more people get tested and treated?</p>
Kim	<p>Obviously, many have ongoing concerns and feel frustrated by limitations of current practices since most are minimally effective. With projected levels of hearing loss increasing over the next ten years, hopefully better treatment will arise since the market is growing. This area of medical care needs expedited since it's been neglected for so long, mostly because it's not as profitable. Being told to begin yoga, learn</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>meditation, or 'get over it' is not appropriate support for those struggling with hearing loss.</p>
Michael	<p>Audiology clinics need to provide counseling for both the person with hearing loss and the normal hearing spouse or other close family members or friends. Hearing loss requires learning coping strategies that both parties need to learn. I have needed hearing aids for about 20 years as a result of typical age-related sensorineural hearing loss. My normal hearing wife and I have had to work through the coping strategies pretty much on our own. It would be good to have explicit support.</p>
Sheila	<p>I definitely would like to see hair cells regenerating. As I get older, my hearing loss is getting worse, and would love to have something to even saving the little hearing that I have. Cochlear implants do not interest me.</p>
Lisa	<p>Yes! Echoing Joy's comments about the water. A hearing device that allows for hearing in the water would be amazing! We live near the ocean and since onset of hearing loss, my son doesn't enjoy the water anymore. It's a fearful situation for him because he can't hear danger or anyone trying to communicate with him in the water. Would love for people living with hearing loss to enjoy the experience of swimming in the water, lakes and or in pools.</p>
Jim	<p>One of my biggest frustrations that needs to be mentioned is the difficulty using speakers found at drive-up windows found at banks, pharmacies, fast food restaurants, various self-service kiosks and others. I simply can't understand the speakers and speech reading is not possible.</p> <p>I am a veteran with service-connected high frequency sensorineural hearing loss in the severe to profound range. VA [U.S. Department of Veterans Affairs] provides good audiology care for me. I use bilateral hearing aids with telecoils and several phone apps. I have begun to learn American Sign Language (ASL) but the lack of general ASL use detracts from ASL use as a practical means of communication.</p> <p>I wish there was a better understanding of hearing loss by the general public. When I tell people that I can't understand them they just continue to talk and I still can't understand. Some of the worst offenders are in the medical providing community.</p>
Lisa	<p>Bluetooth hearing aids have been such an upgrade for my teen son! He has bilateral sensorineural hearing loss caused by his genetic kidney disease, Alport syndrome. He's been living with hearing loss since age 11, now 18. Other helpful tools: his 'Roger' pen that can be set down on a table in restaurant or in a group setting at school to weed out background noise especially in settings with terrible acoustics. A huge improvement over the big, clunky FM system he used to use at school, which caused him embarrassment. A BIG help has been his smartwatch that allows a "vibrate" option so that he can finally set his own alarm to wake himself on time for school or work commitments. It allows him independence so that he doesn't have to depend on a parent anymore to wake him up, which made him feel so dependent.</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

Michelle	I'd like to stress the importance of telecoils in current/future hearing loss technology/devices. Many of the panelists/callers emphasize their use of/benefits of technology to improve their hearing, but not many mentioned telecoils. While Bluetooth is also valuable, the telecoil is the only/stellar method for hearing in large venues and with loop systems, which we need a lot more of.
Dan	Re: doing nothing medical or technological to manage my hearing loss, I'm a concert sound tech. My hearing loss is from 40 years of exposure. Hearing aids would simply up the volume of the failing frequencies, speeding up the deterioration. I can't really consider anything short of hair cell regrowth from stem cells or similar. I carefully limit my exposure and bide my time.
Ray	One technology that I am really looking forward to although I doubt it will be available and approved in my lifetime, is the ability to use the brain to segregate the speaker in a group that I am listening to. I have heard of some research on using brain waves to feed into the hearing aid or CI [cochlear implant] to be able to focus on a particular speaker like normal hearing people can.
Janine	I am relieved to hear from others today about the fatigue they experience in the process of moving through their everyday lives just trying to hear. I am exhausted by evening. Thank you for sharing this aspect of hearing loss.
Robert	The guy that's talking now, who says the audiologists do not spend enough time adjusting his hearing aids and require too many visits, is really advocating for users to have more ability to adjust their own hearing aids. When I had hearing aids, I bought the programming equipment and programmed myself... that was the best money I ever spent!
Brenda	All hearing aids needs to have t-coil technology! More importantly, hearing aid dispensaries need to recognize the importance of this technology and teach their clients on its many benefits!
Tony	<ol style="list-style-type: none"> 1) Communicating during COVID-19 has prevented me from scheduling a long overdue colonoscopy. The receptionist has a mask plus there is a window between us. 2) Caption quality is poor, especially with recorded movies. No reason to not be perfect. I avoid people, I do not want to avoid the TV. 3) No compatibility between the accessories from hearing aid manufacturers. 4) Repair of an aid or accessory that requires a return to manufacturer results in at least five days without hearing. 5) Hearing on phone is difficult with accents. Plus, there are those automated messages that do not wait long enough for a response due to delayed captions. I've been disconnected many times. 6) I avoid fitness classes since we need to hear instructions but the risk of sweat damage makes me avoid these interactions.
Leo	I have profound hearing loss, only 5% left. I wear a hearing aid and it helps a little...my wife must write to me, but no one else wants to take the time to write, it has caused a

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>problem in communication. I get tired and depressed because it is a strain to hear what little I can hear...and we cannot be with more than one couple...</p>
Paula	<p>Wow! Having just heard Darja's comments, I'm realizing that at 73 years of age and also a bilateral cochlear recipient, I'd never really considered that my husband and son and his family will not know the how/why/etc. of my cochlear implants and processors. I need to get moving on that.</p>
Kim	<p>I'm a teacher who has experienced bilateral sensorineural hearing loss over the past eight months in range of moderate to moderate severe. I've been on FMLA [Family Medical Leave Act] for the past two months attempting to adjust to my new 'normal.' Hearing aids are devices, not truly treatment since they merely enhance what's left. Please strive to actually help us improve our hearing and do more research regarding root causes. Most of us with this condition will not know what caused it. Even with accommodations, how will I be able to keep students safe when I'm struggling to function in the workplace? I'm 55 years old and wanted to work until retirement. Please note our frustration, not just patronizing our ability to be resilient and adjusting.</p>
Theresa	<p>My husband only has 5% hearing left...we tried signing but did not work...we are having a lot of difficulty communicating. He now has developed multiple myeloma which makes it more difficult because he cannot understand what the doctors are saying. I go with him all the time. And when he is under stress, his hearing is much worse. Do you know if they are developing any drugs or stem cell for this? No one understands, it is a hidden disability.</p>
Wynne	<p>What specific activities of daily life are most important to you that you are NOT able to do or you struggle with due to hearing loss?</p> <p>I struggle when I go to public events, theater productions, lectures, etc. Even though it is an ADA requirement to have 'assistive listening systems,' not every venue/location has a system that is working, have knowledgeable staff, or have the AV sound system balance.</p> <p>For example, I went to <i>Potted Potter</i> and only understood one joke out of the whole production. I used an FM system with a neckloop. Frustrating especially since it was a gift.</p> <p>In contrast I went to another production at a different venue and understood every word. I had tears of joy. So happy.</p> <p>The locations/ venues are not consistent and I never know what to expect, nor the time I will need to advocate.</p>
Jean	<p>I have a hardly known condition, which is the latest to affect me along with my sudden hearing loss, vertigo, possible Ménière's disease, tinnitus. Two years ago, I suddenly lost the ability to hear male voices, in one day, though I'd lost the higher pitched voices before. But the extra bit was and is diplacusis, meaning in that my inherent sense of pitch broke into two pitches, one in each ear. The meaning of this is that all music</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>sounds off pitch, off. People singing are singing off key. Music I know well is not recognizable to me. I have to ask people what the music is, if I know it, and then I try to remember it, to attempt to link it to what I'm hearing. It makes me dread most forms of entertainment because they are accompanied with music which isn't music. But music is everywhere, not just in entertainment, it's everywhere. I can no longer play piano and hear the music right. I can't sing because I can't hear how it should sound. There is almost no research into this condition.</p>
Janet	<p>As a parent of a now young deaf/hard of hearing adult, she has found her support through technology, through Deaf community, through finding what works for her in her school, social life, and now in the workplace. There is no one answer for all people, and at some level she has had to find her own self-identity, acceptance and empowerment in this journey. As a parent, I was helped so much by parent-to-parent support, was a strong advocate, and now my daughter is a strong advocate for herself as well. We have found joy in the journey, along with the challenges. This journey is multi-dimensional, and not just to be seen through the medical lens.</p>
John	<p>The general public does not distinguish between partial and total hearing loss. When I informed my employer that I had profound hearing loss, they offered to provide me an ASL [American Sign Language] interpreter in meetings. The problem is that I speech read, rather than sign.</p>
Ray	<p>When you did the polling for most difficult aspects, my first one is, like the majority, understanding in noise. But the second one was not on the list: using a phone. It is particularly challenging when using cell phones. Even with captioning phones, it is a real challenge that I mostly avoid. The captioning is far from accurate. Also, I am bilingual and, even when the captioning phone supports Spanish, it takes so much time to switch that often the conversation is over before the captioning in Spanish starts.</p>
Teri	<p>I am a retired hearing loss resource specialist in the Houston, Texas area. However, I recently received a FaceTime call from a student at University of Houston who is in her last year doing her student teaching at an elementary school in the second grade. She was telling me that she was having a difficult time because all the children are wearing masks and she needs to lipread in order to hear them. She had a remote captioner that did not work because the captioner could not hear the children's soft voices. Then the school provided her with a remote sign language interpreter, but the interpreter also could not hear the children's soft voices. She did not pass that course and they are asking her to repeat it next year.</p> <p>This is definitely a hearing loss impact. I did not know how to help her. But this is an example of a very dire impact of hearing loss during this pandemic.</p> <p>I forgot to mention that she also used an FM system but then these young little children learned what it was and started talking louder. They would even make fun of her and</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	whisper because they knew that the captioner or the interpreter would not be able to hear them.
Mary Ellen	At church I miss comments, jokes, and everything. my comments to the church leaders do nothing and i have even been active in finding a solution. it is frustrating.
Wynne	What specific activities of daily life are most important to you that you are NOT able to do or you struggle with due to hearing loss? I struggle with retail and services (banking, vet, groceries, etc.). This is due to reverberation of the physical sound space AND background noise AND people not speaking clearly (then add a mask problem...). I do a lot of faking and try to figure out if the missing information is okay to do without or whether to repeatedly ask for repeat.
John	Beaming audio from my smartphone to my hearing aids via Bluetooth has been transformational. It's a far better solution than using headphones. I can more completely comprehend speech and music.
Joy	Q3. Specific activities of daily life: I wanted to explain why I chose 'Other' for my 3rd option. I can't hear my cats purr, the birds singing, or people coming up behind me when I go hiking.
John	I am a native English language speaker. I have difficulty understanding others who speak with an accent.
Robert	I selected 'Other' because I'm aware that I cannot overhear or eavesdrop on conversations like people with normal hearing.
Julie	Without going 'visible' with my hearing loss by using a remote microphone with my hearing aid and cochlear processor in all social settings, my social life would be completely destroyed. The stigma that continues to be associated with hearing loss, especially of adult onset, is a huge barrier. The mental health aspect needs far greater attention and understanding. We have to realize that this unfortunate 'stigma' is related to not getting treatment. How do we change this when hearing instrument advertisements market denial by focusing on size rather than capability?
John	In an attempt to communicate with me more clearly, some people exaggerate their mouth and facial movements. Rather than being helpful, this inhibits my ability to speech read.
Gen	music is no comfort or therapy anymore. sounds that do manage to come through are bothersome noises. captioning is intermittent and often unavailable/inaccurate... now heavily dependent on eyesight and keeping brain functioning in old age
Mary Ellen	I have trouble getting accommodations or my hearing loss, i.e., church, public programs, etc. this means I cannot appreciate it fully or participate.

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

Ellie	<p>My inability to hear (despite wearing bilateral hearing aids), doctors' orders as they passed by me, and on the telephone. Doctors with accents are extremely difficult to understand, leading to embarrassment from asking them to repeat. Ultimately, this, more than anything attributed to my early retirement at age 58.</p> <p>My nursing career could have been extended if not for this disability.</p>
John	<p>Frequently, I find myself apologizing for not hearing comments, directions and feedback in public settings. Occasionally, people find my misunderstanding humorous. This hurts my feelings.</p>
Ann	<p>Social isolation - can't comfortably do restaurants, gatherings of any type. Initially had great denial - stopped watching TV, socializing without understanding the reason was my hearing. Also, needed to be taught it was OK to ask people to repeat themselves, speak louder.</p>
Munro	<p>I am 85 and have age related hearing loss and not protecting my hearing from loud woodworking tools. I have a CI [cochlear implant] in my right ear and I am seriously looking into getting the left ear implanted. I qualify for the Medicare insurance. I live in a retirement community where the most frustrating I experience is I know people who I have been friends are pulling away and avoiding me because I can't hear what they are saying. I am also a former music teacher and I find music is not satisfactory or what it used to be like.</p>
Gen	<p>I am the sole caregiver to spouse with dementia and mobility impairment.</p> <p>It is extremely frustrating and stressful not being able to hear him and generally, being very difficult getting help for both of us due to my inability to hear.</p> <p>Bothersome, also is the possibility of myself having dementia ... I know firsthand the problems I/we would have to depend on others for assistance.</p>
Arlene	<p>As a CI [cochlear implant] user for the past 23 years, I know my strengths and communication challenges - and that impacts my choices on activities socially and community involvement. I chronicled my experiences in my two books, well known among the hearing loss community. But it's always problem-solving—and being outspoken and upfront about my needs.</p>
Joanne	<p>Appreciate what's been said. What's ironic is that today's closed captioning is out of sync with the speaker, so I'm struggling to listen and read the closed captions since they are out of sync. So far, hearing works better. I too retired early because of hearing loss. And I stopped lecturing because, depending on the acoustics of the room, I couldn't always hear student's questions no matter how close the speaker was.</p> <p>Background noises vary greatly and some rooms were much more challenging than others.</p>
Jamie	<p>It is nearly impossible to obtain accommodation in medical settings, no matter how small the accommodation requested. Nurses continue to call my name from a far-away</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>door, to talk with their backs turned, to get annoyed at me when I explain over and over that I cannot understand. Doctors will not write down what they say. It is just as bad in ENT offices as at the dentist. Complaining up the chain of command has led to my being assured things will change, but they do not. It is exhausting and maddening and scary how little medical professionals care if I can hear or understand.</p>
<p>Wendy</p>	<p>Of all the symptoms that you experience (or your loved one experiences) because of hearing loss, what are the 1-3 symptoms that have the most significant impact on quality of life?</p> <ol style="list-style-type: none"> 1. one symptom is the inability to localize sound. 2. another is the inability to hear in background noise. 3. inability to hear fine musical pitches. <p>How do these symptoms impact specific activities that are important to you?</p> <ol style="list-style-type: none"> 1. I always have to ask people for help to find things - like my car in a parking lot. 2. I avoid a lot of group conversations and missed out a lot on social life growing up. 3. I can't fully participate in musical ensembles the way I would prefer because of this inability to hear fine musical pitches. <p>What are you doing (or what is your loved one doing) to help treat hearing loss, and how well are those treatments working?</p> <p>What are the most significant downsides to those treatments?</p> <ol style="list-style-type: none"> 1. I have bilateral cochlear implants. 2. The downside to the CIs [cochlear implants] is that I think I cannot take advantage of upcoming medical treatments such as gene therapy.
<p>Tatiana</p>	<p>Hearing loss affects my quality of life by making it difficult to communicate with strangers. I can't talk to new people or else I won't understand what they are saying. I also experience constant low tones ringing in my ears constantly. This symptom used to disturb me greatly. Doctors have told me that this new symptom was due to my hearing loss progressing. But they can't tell me why my hearing is progressing in loss! There is still so much to learn scientifically about hearing loss. Something that would help me is increased accessibility in public spaces, such as automatic captions, that actually work! Technological accessibility for the deaf would change so many lives, and it wouldn't be that difficult to implement with the captioning technology that is possible these days.</p>
<p>Bill</p>	<p>My wife and I have moderate to severe hearing loss and wear state-of-the-art hearing aids. Our loss greatly affects our lives. Despite the aids, we suffer from a major communication 'gap.' We need to work really hard to understand each other, often still mishearing what we are saying to each other. Needless to say, in addition to incredible effort to hear each other, this leads to great frustration and worse 'fights' due to not understanding what each is saying. We now need to be in the same room to have</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>conversations--no more shouting down the hall for instance. We now avoid crowded rooms especially restaurants, because these are particularly difficult situations. We love our walks in the woods, but we know that we are missing the sounds of birds, rustling leaves and the wind that we recall in our youths. Hearing aids have helped but quite incompletely. Volume is simply not enough. Both of us can't tell the difference in Amazon Alexa's answer to the current temperature—'fifty-five' or 'sixty-five' even if we maximize the volume. How annoying! How can we restore hearing at its roots? It seems this will be the only way to regain what we have lost--a precious connection to life and most dearly, our family and friends.</p>
<p>Candace</p>	<p>As a parent, I feel the most dramatic long-term impact is on perceived capabilities in the workplace. Despite the investment in the education of children who are deaf and hard of hearing, I find many employers have difficulty looking past an individual's perceived limitations to embrace the many of the skills an individual who is deaf/hard of hearing can bring.</p> <p>I also feel another long-term impact is on potential friendships/relationships which can lead to feelings of isolation and eventual acceptance of lack of relationships.</p>
<p>Eloise</p>	<ul style="list-style-type: none"> • I was born with hearing loss in 1952. • Caught viral meningitis and influenza X2 • Two brain aneurysms in the Circle of Willis • Never tested until year 2000 for bilateral moderate to severe hearing loss – age 48 yrs. • Given hearing aids – allergic to what was in the ear X 3 sets of aids. • Developed migraines over the next 5 years from wearing hearing aids. • Noted I had tinnitus in both ears – never went away • Diagnosed officially with Migraine syndrome – treated with BOTOX injections • Began falling, having vertigo, hyperacusis, upgraded hearing aids to streaming Resound GN / iPhone Tinnitus disabling from ototoxicity from sepsis treatment – using all modes of treatments to decrease noise annoyance – on the piano – sounds like rushing noise at three octaves above middle C E flat. • I have between 10-20 physicians at Tampa General Hospital System that treat my needs ranging from audiology to vision (MVA damage) I worked for 40 years without an accommodation in all tracts of nursing. • NO ONE sought to tell me that I had hearing loss until one physician who understand that I was working so hard to listen and track what everyone was saying, reading their lips and adjusting my life around everyone. I had headaches all my life just trying to hear but I just didn't know what was wrong with me. I used cued language to try to figure out what was going on around me just so that I could get by. <p>My wish:</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	<p>Testing for hearing loss--why wasn't I tested as a child when I was young?</p> <p>Hearing aids/ cochlear Implants – I had to use them to hear – so why aren't others using them? Because supply and demand doesn't work with people denying they have hearing loss. I wonder why that is? Advertisers telling us that we don't want to show anyone that we have hearing loss. Or we want the tiniest one in the ear for convenience? Baloney. One buys it, wears it, and doesn't like it because it doesn't work. It goes in the top drawer and that's it. Terrible advertisement for a tragic need of the brain that goes to mush. The longer you wait the worse it gets. I am living proof.</p> <p>Truth in advertisement is what we need. THE RAW TRUTH.</p> <p>The more people are able to purchase the right hearing aid for their hearing needs the better. Everyone has a specific need depending on the testing that is available – there are 5-6 tests that will give them a full picture of just what their loss is. Then with that, they can fashion a story of what type of aid they should get and match that to it. And audiologists can and should be doing that. Are they? NO... There is no uniformity to their effort to get on the bandwagon to make sure all of the people in the U.S. are getting what they need.</p> <p>Education on what is available, addressing the issues of hearing loss, what hearing devices do and how they are work, how a person should be caring for them since they are computers. Audiologists, Hearing Instrument Specialist, Peer Mentors and our Hearing Loss Association of America Chapters comprise the team that are available to help and work with anyone with hearing loss--no matter what age.</p> <p>I started with HLAA when I first learned about my hearing loss and now have been a leader with the organization for some time. I will stay on until I die but my passion is that all of the government agencies listen to us and step up to the plate in recognizing that hearing loss is the third ranked epidemic here in the U.S. We need everyone to understand this is serious business. Lives have been lost due to suicide dealing with tinnitus and hearing loss (Vets, elderly, young people). The elderly die from depression and dementia without treatment. So much is on the table here. The momentum is now.</p> <p>You all have the opportunity to make a difference in the lives of the next generations who already have hearing loss because of the NOISE in our world. We need to establish that this is the Number One enemy. That begins with you.</p>
Carole	<p>Obstacles in getting to services (health services, retail services, insurance providers, government services) when using the voice telephone is imposed on me. For really important calls where I must be sure I understand correctly, I need a hearing person with me, and in times of COVID-19, this is often really difficult.</p>
Sarah	<p>Meetings with a group, e.g., book club, lectures, plays in auditorium, are difficult. Even with hearing aids. I lose my hearing aids because of other things around my ear (masks, hat strings, sunglasses, long hair.) I have small ear canals and pinnae.</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

<p>Gregrie</p>	<p>Began 1990 to now profound loss. Way down now 16% after Chemo 2 years ago. I would have chosen chemo over hearing-but even though I came with hearing dog, didn't tell me it would get worse.</p> <p>Tinnitus- if that would go away, I believe I would hear much better.</p> <p>Did not know about meds making worse or better. Dr House-both say can't tell why I lost hearing.</p> <p>Sick to death of ads saying, "buy this—end tinnitus." Or improve hearing.</p> <p>Isolation is the worst. Live TV captions horrendous- why even try?</p> <p>Phone —most businesses still aren't trained. Hate to call! Some force it- no online chat!</p> <p>Treat hearing loss?? There is no treatment? You mean how do we adjust to living in world that moves on and gives band aids to hearing impaired.</p>
<p>Sara</p>	<p>I have a cochlear implant and a hearing aid. Having to ask for repetition or clarification. It takes time to do this and the person I am talking to needs to have patience. It is present whenever I am communicating. I let people know that I have hearing loss. I have to remind people I have hearing loss and that they need to be mindful of that: speak up at a moderate pace.</p>
<p>Isaac</p>	<p>I'm in need of hearing aids but because I'm allergic to plastic (mostly hard plastic) nobody wants to be responsible for ordering the hearing aids.</p>
<p>Marcia</p>	<p>Lack of understanding speech.</p> <p>Unable to enjoy music.</p> <p>Captioned phones to enhance hearing.</p> <p>Group setting if there is no loop system installed and lack of loop systems in public settings.</p>
<p>Jess</p>	<p>The most disparaging symptoms of experiencing changes in hearing levels and deafness (particularly late-onset) are those psychosocial challenges faced while enduring systemic and internalized ablism, oralism and audism, which permeates every level of diagnosis and treatment in modern medicine. Long-term consequences of chronic social isolation due to stigma-enforced communication challenges can lead to severe depression, anxiety and the development of mood disorders and/or suicidal ideation. Deficit-based interventions such as amplification technologies are touted as 'cures' to deafness and patients like myself are told our hearing levels are 'fixed' by the accommodated decibels of hearing aids, and there is little discussion for the challenges experienced by patients relying solely on external technology with little to no support to accommodate social or psychological needs throughout life transitions adjusting and to disability.</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

Phyllis	<p>Because much of my somewhat unique hearing loss is in the lower rather than higher register, I have a great deal of trouble hearing men. So it is consistently hard for me to hear my husband! We are both above 80 years of age, and his voice has gotten lower and lower (and he mumbles). This continues to be a source of frustration between us. He also forgets to keep his hands away from his face and forgets to face me when talking.</p> <p>The same issues affect my ability to hear other men friends. No hearing aid I have ever used has helped overcome the problems with hearing loss in the lower register. What can I do? Are there hearing aids available that address this rare problem?</p>
Alan	<p>My hearing is considered normal. I live with my mother, who is 97 years old and has severe/profound hearing loss. She is bimodal (hearing aid and cochlear implant) and has difficulty understanding speech in ideal situations. She is not one to easily accept technology. Still, she is starting to realize that she will need help (using Hearing Assistive Technology - HAT) to continue to engage with people.</p> <p>What is the most significant impact on her life? It is social isolation. She spends most of her day reading or working on word puzzles and limits her interaction with people she knows she will have a difficult time communicating.</p>
Billie	<p>I have hearing loss caused from severe osteoporosis or medicines. I have had three sets of hearing aids. Can't hear on any of them unless I put my fingers in my ears. Can then hear great. I have just had molds made of both ears, but they aren't back yet. I think the regular hearing aid tips aren't touching the right place. That's my story. Thanks.</p>
Mary	<p>Of all the symptoms that you experience (or your loved one experiences) because of hearing loss, what are the 1-3 symptoms that have the most significant impact on quality of life? Difficulty hearing people with masks on--I'm continually missing the punch line--or the most important part of the communication. How do these symptoms impact specific activities that are important to you? Communicating with my medical providers to understand what they are recommending. What are you doing (or what is your loved one doing) to help treat hearing loss, and how well are those treatments working? Getting acupuncture for hearing loss and taking TCM herbal formula for hearing improvement. Online and in-person Reiki. Use of hearing aid (provider didn't recommend one for my right ear). Watching for clinical trials. Did participate in one on supplementing aldosterone several years ago. It seemed to help but became increasingly hard to get at any price. What are the most significant downsides to those treatments? Can't get them often enough to make a significant difference--though I believe they are helping. Although I don't believe my hearing loss is age-related, I haven't been able to get into a clinical trial BECAUSE OF MY AGE. This causes me much resentment.</p>
Lars	<p>My hearing loss doesn't show up on a standard audiogram and is probably 'hidden hearing loss.' The most significant symptoms are hyperacusis/noxacusis and tinnitus.</p>

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

	They have left me housebound for several years, unable to do most things I used to because of the pain. I don't do any treatment. There are no treatments for this at the moment.
Alexandre	<p>I experience many symptoms that hinder my senses. I suffer from hidden hearing loss, tinnitus and depression at the young age of 19 years old.</p> <p>The worst symptom is tinnitus by far. It makes it harder to follow my classes, makes me heavily depressed, causes suicidal ideation and many more. It has essentially turned my life upside down. And as of now, nothing can be done and it can only get worse if I expose myself further to loud noises. Thus, I am afraid everyday of a worsening and have withdrawn from many social activities that people my age engage in (parties, concerts etc.).</p> <p>No effective treatment has ever been administered to me which is highly despairing.</p>
Rand	I experienced ototoxic ear damage almost a year ago, and as a result, suffer from severe loudness, hyperacusis and tinnitus. My quality of life went from 10, to negative 10, in just a matter of months and continues to fall. The circumstances of my accident are traumatic, but even more traumatic was learning that the ear is so under-researched and inaccessible by modern technology. And that there is little hope. There are no treatments at all for what I experience. Anything that does exist is outdated, experimental, and a 'band-aid.' I and countless others have been forced to become hermits and sacrifice our livelihoods because we have no medical hope, nor do we receive the medical recognition and respect we deserve. I cannot drive, shop, go outside, bathe, enjoy music, or even exercise. The time has come for this field to break ground. For me, a year has felt like an eternity. There are others who have waited far longer than I. We need help, and we need it fast. We need our lives back.
Linda	Tinnitus and hyperacusis often accompany hearing loss and have a negative, if not devastating, impact on quality of life. Having these conditions is a monumental challenge because they are externally invisible and often friends and family do not understand the deep depression that can occur. There are no effective treatments that work to decrease the tinnitus precept. I was a sufferer who had difficulty habituating and was told by an ENT physician that tinnitus was not the problem it was my reaction to it. This type of belittling patient treatment is not necessary, medically effective treatments ultimately leading to a cure are necessary.
Genevieve	Both my husband and I have hearing loss, mine more significant. I have a cochlear implant on one side, he wears bilateral hearing aids. The words missed in our conversations often lead to total misunderstanding. So far, no divorce! Fifty-five years of marriage helps to keep us together but hearing loss does not help us to maintain an even keel.
Dan	Hearing devices simply hit already exposure-damaged ears with louder sounds. How can that not hasten worse hearing? The only solution I am interested in is something to regrow the damaged and missing cells.

**Participant Written Comments Submitted Prior, During and After the May 25, 2021 HLAA
EL-PFDD Meeting**

Ali	I am 44 years old and contracted the mumps virus in July of 2018, causing profound deafness in my left ear (Right ear was not affected). This has caused extreme tinnitus, balance deficits along with the single sided deafness. Also, due to the pandemic, I had to leave my job as the mask requirements hindered me from reading lips in a loud environment and performing my job functions. This hearing loss also caused me to become less social, as being in groups is difficult when multiple conversations are taking place at the same time. I currently use hearing aids, but they offer little help as they do not always function properly, especially when masks are required because they tend to move and will stop working.
Christiaan	I have two symptoms that negatively affect my quality of life: tinnitus and hyperacusis. My tinnitus and hyperacusis are incredibly severe. I could say with certainty that I do not have a life anymore. I had to stop working, studying and had to move back to my parents because of this. Due to my tinnitus, I have difficulty sleeping and concentrating. It has negatively affected my sleep, which makes me sleepy and drowsy throughout the day. As for my hyperacusis, it makes it difficult to meet with people somewhere where it is loud or busy. My ears can't handle that. What treatments are concerned: I have followed a course in TRT and CBT but it was not successful. The severity is on such a scale that I'm not able to live with these symptoms. I cannot habituate to this. My only hope rests on the medical breakthrough of hearing regeneration.
Nuno	Worse than hearing badly, is having to live with tinnitus, not being able to rest makes us tired every day.
Jane	As a result of acoustic trauma, I now suffer from tinnitus and hyperacusis - these are the symptoms that have by far the most significant impact on my quality of life. In particular, I suffer from reactive tinnitus, and both loudness and pain hyperacusis - in the latter, sound can cause prolonged pain that results in burning and stabbing sensations. These symptoms have a tremendous impact on my life - I find it difficult to socialize or be carefree as I constantly have to be alert to noise that will trigger my tinnitus or hyperacusis. I especially struggle with high-frequency sounds and artificial audio - this makes it difficult for me to use a phone, video call, watch TV, or listen to music. I am currently unemployed and worry about my ability to maintain employment. I am basically rendered unable to function like a normal person. I have tried psychological help and sound therapy although these treatments have been of limited use. Sound therapy, in fact, worsened my condition and there is evidence to suggest that it is of limited use in treating hyperacusis with pain. There is an urgent need for biomedical solutions to address these devastating sequelae of hearing loss.
Luke	Symptoms of hearing loss that have the most significant impact on QOL:1. PAIN HYPERACUSIS (Noxacusis) 2. Hyperacusis 3. Tinnitus. How the symptoms impact activities:The symptoms have made it extremely difficult to conduct work, enjoy leisurely activities, socialize, enjoy hobbies from when I had normal hearing. Having both levels of hyperacusis and tinnitus means constantly having that weight of making

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	<p>the condition permanently worse take the forefront. Oftentimes, avoidant behavior is the only resolution; or coping with extreme levels of anxiety. I have given up several hobbies and pastimes because even with considerable hearing protection present, the activity still aggravates both the pain, hyperacusis, and tinnitus too much to continue doing so. What am I doing to help treat hearing loss: there is no treatment. Only using protection (ear plugs) to conserve hearing and slow the degradation from normal wear and reduce the impact of loud noise on already damaged/worn cochlea. TRT and CBT are not efficacious to spend time on. The reality is slowing the wear (and the increase of tinnitus, hyperacusis setbacks) is the optimal solution. Ear plugs are only so effective; even when worn when appropriate, sound insults can still lead to setbacks / further deteriorated hearing. What are the most significant downsides to those treatments: The "treatments" like CBT / TRT are simply coping mechanisms but DO NOT address the issues with the underlying biology from SNHL. Hearing aids apply only to a specific group but do not truly resolve tinnitus and aggravate hyperacusis issues/trigeminal pain from noxacusis.</p>
Johnny	<p>I have lost my hearing in both ears and I cannot afford a hearing aid at all. I have insurance but it will not cover them at all and I cannot afford to finance them at all just need some help to get them.</p>
Eileen	<p>Loss of social life. Life is lonely and isolated wear hearing aids with Bluetooth</p>
Roz	<p>I sometimes mis-hear certain consonants, which causes my mind to wander off to consider the word I think I heard, which can be amusing or disconcerting. This has unintended consequences, as it appears that I have lost the thread of the conversation (which sometimes I have, if I don't guess the right word fast enough) and leads folks to worry I am not all there. I need to learn to stop the conversation until I get it right. But that is not always easy.</p>
Ron	<p>I have some hearing loss, but it is the tinnitus that is the most bothersome. What is the best hope for stopping tinnitus as of today?</p>
Mary Anne	<p>I have trouble even with hearing instruments. There must be something that can work.</p>

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Joy

My hearing loss symptom with the most significant impact on quality of life would be tinnitus. It is nearly impossible for me to hear anyone whispering or quiet conversation or little noises like the birds singing or my cat purring. These sounds are completely lost among the persistent buzzing I live with on a daily basis. At times, especially in the morning, the noise blockade is so noticeable I can't hear a single word my husband or kids say to me until I've been awake long enough to get my hearing aids in. It makes some of the joy of simple pleasures like 'sleeping in' a bit less enjoyable. To be frank, the idea of whispering sweet and nothings no longer exists in our marriage - it is more a 'yell it directly to me ear' or often receives a 'what?' in response, not very romantic! I wear bilateral hearing aids and they help a LOT, but they don't remove the tinnitus completely and they only go so far to help with speech discernment. Certain voices and accents make it excruciatingly difficult to carry on conversation. Group conversation is overwhelmingly challenging to the point that I often avoid it or just 'check out' if I'm not hearing well with the people and environment. Building a social existence in the hearing community with a hearing impairment ends up feeling a lot like second fiddle and/or a burden to the conversation. No one wants to feel burdened or perceived as stupid, so as a hard of hearing person I tend to self-isolate at times especially with people that don't know me well or understand my needs. I have three school aged children, so this impacts the social world my children are experiencing through me as well. I wish it wasn't the case, but it is. Aside from the program limitations of a hearing aid and the brain-sound connections that aren't fully up to par as a result, the most significant downside to the hearing aids are: not being able to wear them in water, batteries that die before the end of my day and discomfort caused by mask/glasses/aids all competing for ear space.