



HLAA's Externally-Led
Patient-Focused Drug Development
Meeting Transcript

Tuesday, May 25, 2021, 10 a.m.-3 p.m. (U.S. ET)

The meeting recording is available here:

hearingloss.org/hlaa-pfdd/

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Meeting Transcript

James Valentine, JD, MHS ([00:25:02](#)):

Good morning. My name is James Valentine, and welcome to the Externally-Led Patient-Focused Drug Development Meeting on Sensorineural Hearing Loss. I'm here in the studio with my co-host, Barbara Kelley from the Hearing Loss Association of America, and we're coming to you live from the Washington, D.C. metropolitan area, actually not too far from where the Food and Drug Administration headquarters are located. To open today's meeting, it is my pleasure to introduce Barbara Kelley, the executive director of HLAA to provide some welcoming remarks. Barbara.

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Barbara Kelley (00:25:33):

Thank you, James. Welcome to the Externally-Led Patient-Focused Drug Development Meeting on Sensorineural Hearing Loss. It's my pleasure to be here as the executive director of the Hearing Loss Association of America. For more than 40 years, our mission has been to open the world of communication to people with hearing loss through information, education, support and advocacy. The voice of the person with hearing loss has always been key to our work and has pushed our advocacy goals forward. We've seen improvements in technology, research, and policy and we know the voice of people with hearing loss is important to more advances. Thank you to the U.S. Food and Drug Administration for giving us permission to hold this meeting and for attending today.

Barbara Kelley (00:26:22):

Thank you to our generous supporters who financially sponsored this meeting. It could not have happened without your support, and we are so pleased to have 56 partner organizations for this meeting. They are advocacy and professional organizations, companies, federal agencies, and universities from across the world who support hearing healthcare research and solutions. This is a testament to the enormity of the importance of hearing loss as a global public health issue. This year on March 3, World Hearing Day sponsored by the World Health Organization, the World Hearing Forum published the World Report on Hearing.

Barbara Kelley (00:27:08):

The report shows the financial impact of untreated hearing loss, but it also reports on what we're going to hear today when people with hearing loss share their stories about disruption, and sometimes distress, when communication breaks down, and this happens with all degrees of hearing loss. Ask anyone, there's no such thing as a small hearing loss. Many of you know the popular words from Helen Keller, but it's worth repeating. Helen was both deaf and blind, and as she said, "Blindness cuts us off from things, but deafness cuts us off from people." We realized profoundly the effect of being cut off from people during this past year with COVID-19.

Barbara Kelley (00:27:55):

Many experienced loneliness, isolation, anxiety, and depression which are all associated with hearing loss, and for some people with hearing loss, COVID-19 added another layer of isolation. This meeting today puts an exclamation point on qualitative research which reflects reality. You'll hear today the reality of living daily with hearing loss from those with varying degrees of hearing loss, using different technologies and strategies to go to school, work, enjoy second careers, or retirement life, and to people with hearing loss and your loved ones who are listening today, we invite you to call in or write in during the program. We want to hear as many perspectives as possible.

Barbara Kelley (00:28:47):

Even if it's a positive aspect, we want to hear from you, and as one of our panelists shared ahead of this meeting, our stories are important. We've been pleased to work with the FDA in planning this meeting and here to provide opening comments from the FDA is Dr. Gavin Imperato, medical officer within the Office of Tissues and Advanced Therapies within the FDA Center for Biologics, Evaluation, and Research. This is part of the FDA that oversees new cell and gene therapy products. Thank you Dr. Imperato and welcome.

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Gavin Imperato, MD, PhD ([00:29:28](#)):

Thank you so much Barbara. Good morning everyone and welcome. It's really a pleasure and an honor to be joining you today for this patient-focused drug development meeting. I'd like to first thank the Hearing Loss Association of America, Barbara and all the staff, all of the industry sponsors, organizations, and of course the patients who are joining us. Patient-focused drug development is such a critical element of developing and ultimately, hopefully approving new therapies that have a transformative effect on people's lives. We at the FDA are very excited about the role of patient-focused drug development.

Gavin Imperato, MD, PhD ([00:30:09](#)):

I'd like to give a bit of a background on the whole process of drug development and reflect more specifically on the Office of Tissues and Advanced Therapies within the Center for Biologics, Evaluation, and Research to give everyone a sense of the overall framework for how products are developed, what role the FDA plays, and how critical patient voices are in this process. Most of the time, we hear about the FDA in the media when a new drug or device or biologic is approved, and I liken this to a commencement ceremony if you were to think of drug development as an educational pathway. It's a moment of obvious exaltation because it's the crowning achievement of many years of work that ultimately precedes that official approval.

Gavin Imperato, MD, PhD ([00:31:13](#)):

Of course, there are many years and many steps that are required before a college graduate walks across the stage at commencement and receives their degree, and that development as a person, as a student, as a member of society starts in pre-K. A young person is protean in their worldview, and they go through a series of steps that helps them to form into the complete person who ultimately receives their degree. The same can be thought of the process of drug development. The FDA is actually involved at every step along that pathway, and that's often something that that people in the general public don't see because so much of the focus is on ultimate approval, but we're very involved at every step before that.

Gavin Imperato, MD, PhD ([00:32:09](#)):

This is where the role of engaging with patients and organizations like the Hearing Loss Association of America is so critical, particularly for the products that we regulate within the Center for Biologics, Evaluation, and Research and within the Office of Tissues and Advanced Therapies. The reason for this is manifold. There has been an absolute explosion in our understanding of the basic mechanisms of disease over the past several decades and in particular, genetic mechanisms of disease. There's also been concomitantly an explosion in technologies that have enabled us to think about new types of treatments that years ago would have seemed like science fiction. What's come of that is the possibility of offering new treatments to people for conditions, or diseases that years ago would have seemed impossible.

PART 1 OF 10 ENDS [00:33:04]

Gavin Imperato, MD, PhD ([00:33:03](#)):

And this is extremely exciting. It also presents a number of challenges. One of the major challenges, of course, from our perspective at the FDA is how we ensure the safety and efficacy of new products that

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are being developed. And so a first step in developing our framework for evaluating safety and efficacy of product is understanding the condition. And there's no better way to understand the condition, particularly complex conditions like sensorineural hearing loss that have so many effects on an individual's life, their ability to function, how they feel on a daily basis. And we at the FDA are so excited about the opportunity to hear from patients because their voices are so critical in that whole process of how we think about the safety and efficacy framework of these new therapies.

Gavin Imperato, MD, PhD ([00:34:06](#)):

So I really want to thank all of the patients who are joining us today, your courage, your candor, the work that you're putting into this is tremendously appreciated. It really has enormous value to us. I feel that we often don't, we don't get to express that gratitude, but I'll tell you as a physician, as a medical officer, for all my colleagues, our day-to-day work involves patients. We don't necessarily see or know, but we are in the trenches of making difficult decisions about patients and their lives. And the better that we understand their concerns and their perspective, the better we're able to execute the work that we asked to do from a regulatory perspective. So thank you, personally and thank you on behalf of the FDA, because your participation is absolutely critical. I think of the broad ecosystem of developing new drugs, biologics and devices as a team effort and patients are a critical part of that team.

Gavin Imperato, MD, PhD ([00:35:22](#)):

It's actually astonishing and a bit unfortunate that patient-focused drug development is a relatively new development. For many years in medicine, in the practice of medicine, the voice of the patient was really not seen as a critical element of the provision of care. We think totally differently about clinical practice and also drug development with regards to patients, because the reason the United States Food and Drug Administration exists is to protect and promote the public health of the country. And for conditions like sensorineural hearing loss, we have to hear from patients to understand their concerns and so that we can better execute the regulatory role that we have. So I mentioned to you some broad strokes about how products are developed at FDA. I want to reflect a little bit about the Center for Biologics Evaluation and Research in the Office of Tissues and Advanced Therapies.

Gavin Imperato, MD, PhD ([00:36:19](#)):

So you can think of the FDA as having essentially three large components, of categories rather of new products, drugs, devices, and biologics. There's a lot of complexity, there are many more moving parts to the FDA, and that's a bit of an oversimplification, but I think it's helpful just to understand the broad organization. So drugs are things that you think of when you think of drugs, things that you would purchase at a local pharmacy. It also includes things that would be administered in a hospital setting like chemotherapies, devices, of course are things like pacemakers, implanted defibrillators via a variety of products that can be implanted surgically, artificial spinal discs, valves, heart valves, those kinds of things. And then the final category, which is the most, really mechanistically complex and the most complex from a regulatory perspective, but I think also the most exciting and has the most potential to really revolutionize the care of patients is biologics.

Gavin Imperato, MD, PhD ([00:37:29](#)):

So biologics refers to a diverse range of things that administers to the human body, that are designed to prevent or treat a disease or condition that are derived from some type of biological system. So I'll give you some examples of this. The vaccines that have been recently authorized for COVID-19 under

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emergency use are regulated by the Center for Biologics Evaluation and Research. Products like antivenin, if you're bitten by a rattlesnake. Products like allergenic extracts, if you have allergies and you receive immunotherapy shots. If you had blood loss and were treated in a hospital and you needed an infusion of a blood or another blood derivative, that would be regulated by the Center for Biologics Evaluation and Research. So there are a variety of treatments that one doesn't often think about when you think about a drug or treatment, but they're absolutely critical.

Gavin Imperato, MD, PhD ([00:38:35](#)):

In the Office of Tissues and Advanced Therapies, our particular purview is gene and cell therapies. And as I mentioned earlier, there's been an absolute explosion in our understanding of the genetic basis of disease. What this means from the perspective of developing new therapies is that we're now able to think about targeting things, using gene and cell therapies, mechanisms of disease that we never could before, and that poses a variety of challenges. In the process of helping our industry and academic sponsors to develop their new products, we have an interactive process where we had discussed the clinical development programs and give feedback about how we think clinical trials should be designed, what are meaningful clinical end points, so in other words, when a trial is designed, the purpose is to evaluate its effect, the safety and efficacy of the new products in human subjects. And for the products that we regulate, there often isn't a precedent. Gene and cell therapies are a relatively new arrival on the scene.

Gavin Imperato, MD, PhD ([00:39:53](#)):

And so we have products that are inherently complex because of their biology and their mechanism. And we also have conditions like sensorineural hearing loss that are not typical of what we think of when we think of a disease process. And the role of patient-focused drug development, I really can't emphasize that enough, it's so critical because when we decide on these critical parameters for how we evaluate safety and efficacy, taking into consideration the live patient experience of how patients with a condition feel and function is just so critical. So we're absolutely thrilled to be joining you today. The FDA is not an adversarial monolithic group of people. We're 18,000 human beings and we're patients too. And we have friends and relatives and we are personally affected by so many of the diseases and conditions that we regulate. So I want to assure you that on the other side of that FDA wall, are a lot of very caring, capable people who really go to work every single day with the singular goal of protecting and promoting public health. We exist to facilitate drug development and we exist to serve patients.

Gavin Imperato, MD, PhD ([00:41:20](#)):

So thank you also to the industry sponsors, you're in the trenches, we commend you for all the hard work that you're doing. We don't often get to interact in these kinds of formats where we're liberated to encourage you in that way, because many of our interactions are formal in nature, but please know that you have our support and encouragement, you're advocating on behalf of your patients. The Hearing Loss Association of America is advocating on behalf of patients, and patients, you are the true stars of this show and we commend you for your bravery and for your courage.

Gavin Imperato, MD, PhD ([00:41:59](#)):

We know it's no mean feat to share the details of your personal struggles and how conditions affect you. So we really want to extend our most heartfelt thank you. And again, thank you so much, Barbara, thank you to the Hearing Loss Association of America. We're really very pleased to join you for today's meeting

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and you won't see me on video, but I will be here jotting down notes in my notebook and I very much look forward to sharing them with my colleagues at FDA. Thank you so much again, back to you, Barbara.

Barbara Kelley ([00:42:37](#)):

Thank you, Dr. Imperato and to all the thousands of people who work at the FDA, that was really great to hear that. Now, here to provide a clinical overview of hearing loss is Dr. Frank Lin. He's the director of the Cochlear Center for Hearing and Public Health and professor of Otolaryngology, Head and Neck Surgery at the Johns Hopkins Bloomberg School of Public Health. Welcome Dr. Lin.

Frank Lin, MD, PhD ([00:43:06](#)):

Hello everyone. My name is Frank Lin and I am a professor of Otolaryngology at Johns Hopkins. And I want to thank the Hearing Loss Association of America for inviting me to present to you today on the topic of sensorineural hearing loss to lead off this Externally-Led Patient-Focused Drug Development Meeting. What I've been asked to do today is to give a broad overview specific around sensorineural hearing loss. And what I like to do then is to briefly touch on first, just some physiology and epidemiologic prevalence of hearing loss. Then briefly talk then about some implications of sensorineural hearing loss for children, and then for adults separately. And finally then touch the very end on some of our current approaches to clinical management of a hearing loss. So when we talk about hearing, I think it's helpful to begin what I mean by hearing. And when I think about hearing, I think about hearing fundamentally occurring in two steps.

Frank Lin, MD, PhD ([00:44:03](#)):

On the top left there, that is what a complicated sound like speech looks like. It's composed of frequencies, each frequency has a different intensity as well progress in real time. So the first step per se in being able to hear is what the cochlea does. The inner ear, the peripheral auditory system takes in that very, very complicated acoustic signal and converts that signal, transduce that signal into a neural code that then goes to the brain and the brain then has to decode the signal. So from engineering point of view, all hearing is really encoding in the inner ear and decoding in the brain. Now, when we then talk about sensorineural hearing loss, fundamental to what we're talking about then is impairments in the cochlea. The cochlea is all comprised of primarily post-mitotic cells that can't regenerate, so over a lifetime of exposure to noise, aging, other sort of metabolic or drug insults over time, we can all develop some degree of hearing loss as some of those cells die off and can't regenerate. And this is what we usually mean when we say sensorineural hearing loss.

Frank Lin, MD, PhD ([00:45:09](#)):

Now importantly, when we develop sensorineural hearing loss, the issue is then, it's not only that you can't hear soft sounds for instance, the bigger issue is that there's distortion in that sound encoding by the inner ear. So in the cochlea, instead being able to crisply and precisely encode every single peaks in that sound spectrum program, you see it's a much more garbled, auditory encoding. And that's why if we ever talked to anyone who has a hearing loss, what they'll say to us, they'll say it's not that I can't hear you it's I can't understand you. And the reason for that again, is because the signal that goes from the impaired cochlea to the brain, instead of being a very, very crisp and clear signal, it's a much more garbled signal.

Frank Lin, MD, PhD ([00:45:50](#)):

Now, when we talk then about measuring hearing, it's important to understand there are many, many ways of measuring someone's hearing function. But one of the most foundational basic ways we start with is with something called the audiogram. And what the audiogram does or a pure-tone audiometry does, it basically measures how loud sounds have to be for us to detect them. On the X-axis on audiogram is the pitch of the sound, how the frequency of the sound point from low pitch on the left to high pitch on the right. And then we measure it, each of the different pitches, how loud the sound has to be for someone to detect them. This is in decibels, going from zero decibels at the very, very top of very, very soft sound, all the way to 80 or 90 or a hundred, which is very, very loud.

Frank Lin, MD, PhD ([00:46:33](#)):

Typically, we say that when someone can hear sounds, about 20 to 25 decibels or softer, that's considered normal hearing. 20, 25 decibels is roughly like a soft whisper for instance. And then from there, the sound has between 20 and 40, roughly we call that a mild hearing loss between 40 and 60 or 70, it's called a moderate hearing loss and so on and so forth. Now, a lot of times, the way we'll summarize someone's hearing, especially when classifying someone as having hearing loss or not, we'll classify it based on what average, the four frequencies are most important for speech, which basically 504,000 Hertz, that's where the bulk of speech energy is. And what average, just to give a level of how loud speech sounds typically have to be for someone to detect it. And that's what's called a pure tone average. And a lot of times we'll base on someone's better hearing ear just to be a little more conservative. Obviously the good ear and a bad ear, the good ear is usually how we classify someone's hearing for epidemiologic purposes. Now, when we look at this then, how common a hearing loss is by age decade, this is based on data from the United States, we see that the prevalence of a hearing loss is basically a pure to an average greater than 25 decibel. So which when hearing loss is typically considered to be clinically significant, we see it increased dramatically across a lifespan. And young children, about one to two thousand children are born deaf or with severe hearing loss. So it's obviously just very, very low percentage relatively there. But over the lifetime, as we accumulate aging, noise exposure effects, we see the prevalence of hearing is basically double with every age decade, such that by the time we look at older adults who are 70 years and older, there are nearly two out of every three adults in the United States over 70 has a significant hearing loss.

Frank Lin, MD, PhD ([00:48:16](#)):

Now importantly, if we project this forward now for the next 40 years, we're seeing these numbers increased dramatically. Namely, we're about 40 million adults right now in 2020 having hearing loss and by 2060, 40 million Americans, I mean, 73.5 million Americans are experiencing hearing loss in 2060. And the reason for this growth per se, is mainly because of the growth and the increase in the number of older adults, everyone lives longer. The absolute risk of hearing loss likely isn't going up at all, maybe slightly decreasing, but purely just because of the number of older adults, we're seeing more people with hearing loss over time.

Frank Lin, MD, PhD ([00:48:52](#)):

Now we transition now and let's talk a little more about the implications of hearing loss. I'm going to talk about the implications of hearing loss differently for children than for adults, mainly because they're very, very different populations. When you talk about hearing loss in children, what we're typically concerned about is children who are born with a severe hearing loss, or even profoundly deaf, who have

no access to sound very early in life. And that's important because the way our brain uses sound is a fundamental hierarchy of how we begin to use sound and how that sound allows us to develop language. Mainly the very, very get-go with auditory, you need to have auditory awareness and the detection of sounds in order to detect it. As you learn to detect sounds, you can learn to discriminate different sounds that then allows for recognition of what a sound means. Also allows for identification of certain sounds and the comprehension.

Frank Lin, MD, PhD ([00:49:42](#)):

And importantly, as we think then about children who have early auditory deprivation, early auditory loss, opening a higher level of processing fall and depends on the earlier critical care expense. You can't jump from one level to another, for instance. Now important is, hierarchy also carries four. As we think then about language comprehension, be able to understand, understand what your mother is saying, for instance, that ultimately allows us to learn how to speak, to produce language which then serves the basis later for be able to read and also be able to write, so all functions in a hierarchy. At the same time, this hierarchy proceeds in the right side too as well. For language comprehension fundamentally serves the basis for effective communication between a child and a caregiver, right? The dyadic relationship between a son and a mother or a daughter and her mother and father are critical for that dyadic relationship. And that in turn serves the basis or foundation for development of our later cognition affect and social interaction.

Frank Lin, MD, PhD ([00:50:41](#)):

And because of this long-standing recognition of how important or how detrimental impact auditory deprivation can have on a child's early life, it's basically why we have now, throughout the United States, many parts of the world, we have universal newborn hearing screening. At birth, children are screened for hearing loss very, very early, so that if it is present, we can begin addressing it immediately. So we can progress through these stages, this hierarchy as quickly as possible, as opposed to having a long period of auditory deprivation.

Frank Lin, MD, PhD ([00:51:14](#)):

When we talk then about adults though, it's a bit different. So adults who have hearing loss, we're typically not talking about congenital hearing loss, is the hearing loss that occur later in life, again through process of aging, noise exposure, other factors that lead to hearing loss later in life. Importantly, epidemiologic research now, really over the last five to 10 years now, has really begun to lay the foundation of why this hearing loss is also as critically important for adults as it is for children. Namely, in this epidemiologic studies now we find that hearing loss is consistently an independent risk factor for things like dementia and brain aging, health care expenditures, health care utilization, and also even impaired physical functional risk of progressing to a disability or to a fall or needing a nursing home for instance.

Frank Lin, MD, PhD ([00:51:57](#)):

And importantly, this isn't just correlation, we think in fact, there are hypothesized mechanisms that directly link hearing loss' broader outcomes, namely things like cognitive load, brain structural changes, social isolation, or loss of environmental sound cues. To take you through an example, where a lot of research has been done for the last 10 years, specifically looking at hearing loss and risk of dementia, and again, we think it's not just driven by a common cause or common pathological process, not just a

correlation, we think in fact that the direct mechanisms to which hearing loss can contribute to these much broader outcomes, namely through things like cognitive load, if the brain's constant receiving a much more garbled auditory signal from the ear, we understand how the brain constantly has to dedicate more energy, more resources to dealing with hearing, that degraded signal, and then comes at the expense of our thinking memory abilities.

Frank Lin, MD, PhD ([00:52:46](#)):

At the same time, we're seeing in studies down the middle, that hearing loss can actually lead to faster rates of brain atrophy, which then affects function as well. And finally hearing loss can clearly contribute to social isolation or loneliness, which can in turn affect risk of cognitive impairment, dementia over time. Importantly, this carries over to large epidemiologic studies have really examined this and the best data's come from... the best summaries have come from the Lancet Commission on Dementia, where in 2017 and 2020, they commissioned this very, very large systematic meta-analytic review of all the literature on dementia risk factors. And what the effect that they concluded in two of the reports in 2017, again 2020, has identified hearing loss in mid and late life as being single-handedly the largest risk factor for dementia of all known risk factors are present.

Frank Lin, MD, PhD ([00:53:38](#)):

Importantly, this also carries over to other downstream effects, if we look at hearing loss and health care utilization outcomes or health care cost outcomes, this was a research done in collaboration with the ARP and OptumLabs, we see on average that people with hearing loss have a greater risk of needing ENT visits, of having a longer or a readmission to the hospital over time, longer hospital stays as well as a greater rate of hospitalization over time. And that's directly reflected on health care costs in the bottom right. So these are all health care costs, not relating to hearing loss treatments or non-hearing loss [inaudible 00:45:13] costs.

Frank Lin, MD, PhD ([00:54:14](#)):

We see over two, five and 10-year period that people with hearing loss basically have greater health care expenditures over time. Now this all sort of begs the question then, does that mean, well, if we treat hearing loss in adults, does it in fact reduce the risk of things like dementia and other adverse health outcomes? We actually don't know yet. The reason why we don't know this is from observational studies, you can't tell what the effects of let's say using a hearing aid is, because people are very different. People who get hearing aids are very different from those who don't. It's very hard to disentangle that just from observational data. What's really needed is a randomized control trial where half the people get hearing loss treatment, other half just get sort of a control group, and we see what happens.

Frank Lin, MD, PhD ([00:54:58](#)):

A trial like that is ongoing right now, this is funded by the National Institute on Aging. This trial involved a thousand older adults who were randomized from 2018 to 2019, either hearing loss treatment versus essentially a control group, and they're all being followed now for three years. When this trial is finished in 2023, it'll provide more or less definitive evidence of whether treating hearing loss in fact reduces things like cognitive decline, brain aging and health care costs.

Frank Lin, MD, PhD (00:55:27):

Now in inclusion now, when we talk about the clinical management of hearing loss briefly, our current management really is predicated on, what I'll say is clinic-based auditory rehabilitation one-on-one sessions with a patient and typically an audiologist or otolaryngologist like me, if there's more medical issues involved. And it finally is based on looking at auditory needs to set what the child or the adult needs.

Frank Lin, MD, PhD (00:55:53):

And then finally, sensory management with hearing aids, other type of hearing assistive technologies. For those with more severe hearing losses, who wear hearing aids will be less beneficial is when patients are also evaluated for things like cochlear implantation, which can allow for restoration of auditory input to the inner ear and into the brain. For those with severe hearing loss or hearing aids, it would no longer be beneficial. Now this is a current management, current novel approaches under development right now include alternative service delivery models rather than a one-on-one care in a clinic-based setting. Can we in fact do this by telehealth with a remote provider and or could we have health care extenders like a community health care worker deliver a basic level of hearing care in the community, given if there's so many people with hearing loss, we may need other service delivery models.

Frank Lin, MD, PhD (00:56:41):

At the same time, something currently under development, which is very exciting, this idea of direct consumer access to over-the-counter hearing aids. Right now in the United States, a way hearing aids are regulated is you can really only purchase one, if you go through a licensed provider. With advances in technology over the last 20 years, clearly there is the ability now for consumers to buy a safe and effective hearing aid over-the-counter, but currently these are not available. But fortunately, because of legislation passed in 2017, the FDA is now mandated to issue and draft and release these over-the-counter hearing aid regulations that would ensure that consumers could access a safe and effective hearing aid over-the-counter. These should hopefully be released soon, they were due in 2020, but because of COVID-19, there's been a delay.

Frank Lin, MD, PhD (00:57:25):

And finally, there's also clearly ongoing innovations in terms of the amplification strategies and signal processing for how we can have better algorithms for manipulating auditory signal through a hearing aid or cochlear implant to allow for a clear signal. What's clearly not here in this figure yet, [inaudible 00:57:42] is anything around pharmacologic management of hearing loss, which currently really aren't available, but which may represent a paradigm shift rather than focusing on purely rehabilitation, future drug therapies could potentially be neurorestorative. But then the question is how do we evaluate such technologies or such drugs and how do we evaluate effect whether they are effective for patients with hearing loss. So thank you all for your attention and thank you again to the Hearing Loss Association of America for inviting me to present to you.

Barbara Kelley (00:58:12):

Thank you, Dr. Lin. So, James let's get started. James Valentine is the moderator for today. He's an attorney with Hyman, Phelps & McNamara in Washington, D.C. We're in good hands with James. He was previously with the FDA where he served as a patient liaison, helping bring patient voices into FDA decisions and help to create the patient-focused drug development program. Since joining his firm in

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2014, James has helped plan and moderate more than 35 of these Externally-Led PFDD meetings. We've really enjoyed James being our partner over the months leading up to today. It's my pleasure to welcome James Valentine. James?

James Valentine, JD, MHS ([00:58:59](#)):

Thank you so much, Barbara. And it's such a pleasure to be here today and help in moderating today's meeting. So now that we've heard a clinical overview from a disease expert, we turn to the core of today's meeting, which is to hear from you individuals living with hearing loss and their direct care partners and caregivers about the experience of persons living with hearing loss. PFDD is a more systematic way of gathering patient perspectives on their condition and on available treatments. And as you heard from FDA's Dr. Gavin Imperato, your input can help inform the agency's understanding of hearing loss in order to inform drug development and review.

James Valentine, JD, MHS ([00:59:43](#)):

Today marks the 47th Externally-Led Patient-Focused Drug Development meeting and due to the ongoing COVID-19 pandemic, this is actually the 14th fully virtual EL-PFDD meeting of its kind. With over 7,000 known rare diseases and additional thousands of more prevalent conditions, this is truly a unique and important opportunity for this community. I'm going to describe a little bit about today's meeting, which is one that is an interactive. And so I'm going to talk to you a little bit about what we'll be asking of you and how today's meeting will be organized. First, we'll be exploring the patient and caregiver experience with living with hearing loss and its impacts on your daily life. Then in our second session, we'll bring everyone back together to explore the various approaches to treatment. And we will be asking you for your preferences for future treatment. Within these two overarching topics, what will our discussions look like? Well, today we're going to be using primarily three different methods to hear from you.

James Valentine, JD, MHS ([01:00:47](#)):

First, we're going to hear from panels of individuals with hearing loss. They are going to help share their experiences in order to set a good foundation for the discussion. The panelists were selected to represent a range of experiences with hearing loss and treatments for hearing loss. However, we know that no one panel or a couple of panels could accurately capture the full range of experiences, which is why it's going to be so important to hear from all of you. So we will build on those panelists discussions through a live audience discussion with all of you individuals living with hearing loss, caregivers of individuals with hearing loss who are tuned in live today. We'll ask that you build on what we've heard from the panels, I'll be asking questions and inviting you to provide comments.

James Valentine, JD, MHS ([01:01:36](#)):

This can be done in one of two ways. We'll be providing you with a phone number that you can use to dial in and share your comments live today. We'll be inviting you periodically throughout, and we'll hope to hear your voices. You also can submit written comments at any point throughout today's session, which Barbara will be sharing periodically throughout. You'll see that there's a comment box underneath the live stream onto the webpage for today's meeting. We'll also be joined with a panel of individuals living with hearing loss via Zoom to participate in that discussion as well. And then finally, we're going to broaden the discussion through use of polling questions. We're going to ask our individuals that are living with hearing loss and their caregivers to use their phone to respond. Or if you're following along

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on your computer, you can use a browser on your computer as well. We actually encourage you to go ahead and get on this system now, so that way you'll be there and you can actually stay on that webpage throughout the entire course of today's meeting, as the questions will automatically change, as we move throughout the day. You can pull out your phone and open a tab, or you can open a new tab in a web browser and go to PolLEV.com/HLAA, again feel free to go there now, that's PolLEV.com/HLAA, and we'll be getting to polling very soon, but wanted to give you a head start on getting there. And we're going to use these polling questions to broaden the discussion to everyone and help aid in the discussion. We'll also provide an opportunity to give additional written comments for 30 days after today's meeting using that same web comment form. All of today's input and the written input submitted after the meeting will be summarized in what's called a "Voice of the Patient" Report, which is a summary of today's meeting, which will be provided to the Food and Drug Administration as well as made available more broadly for the research and development community.

James Valentine, JD, MHS ([01:03:42](#)):

One last thing before we get started is to cover a few ground rules for today's discussion. We want to encourage individuals living with hearing loss and their caregivers to contribute to the dialogue. Do this through polling, through phone calls, through written comments. The discussion today will be limited to individuals with hearing loss and their family members and other direct caregivers only. Our colleagues at the FDA, drug developers and clinicians are here to listen. I also want to mention that views today are going to be inherently personal and the discussion may even get emotional at times, so respect for one another is paramount. So to that end, I ask that you please try to be focused and concise in your comments so we could hear from as many voices as possible.

James Valentine, JD, MHS ([01:04:28](#)):

So let's go ahead and get to it. We're going to go to our first set of polling questions, which are some questions to give us a sense of who we have in our audience today. So please go ahead again, pull out your phone, open that browser, or open a new tab on your web browser and go to PolLEV.com/HLAA. And again, these polling questions are for our individuals living with hearing loss and their direct caregivers. So as you can see here in our first polling question, we want to know, are you either A, an individual living with hearing loss or B, a relative or care partner of someone with hearing loss. We're going to give you a few moments to make sure everyone gets into the system. We'll be able to track your responses live as well as incorporate those into the Voice of the Patient Report. So we want to give everybody a chance to answer these questions. Results are still coming in, but as it stands, it looks like, of our members of the hearing loss community today, participation is about a little over 80% are individuals living with hearing loss themselves. And we're seeing a little under 20% as representatives of the community as direct caregivers.

PART 2 OF 10 ENDS [01:06:04]

James Valentine, JD, MHS ([01:06:03](#)):

Representatives of the community as direct caregivers of those living with hearing loss. So, if we can move to our next polling question. So at this point, we want to ask you to answer these questions on behalf of the person living with hearing loss. So if you're a caregiver, please answer this for the person with hearing loss, for whom you care. So, where do you, or if you're a caregiver, the person who has hearing loss, where do they currently reside? The options are A: the U.S. Pacific Time zone, B: U.S. Mountain Time, C: U.S. Central Time, D: U.S. Eastern Time, E: U.S. Alaska Time, F: U.S. Hawaii Time,

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G: Europe, H: the Middle East, I: Asia, J: Canada, K: Mexico, L: Australia, or M: some other region or country not represented in any of the other response options.

James Valentine, JD, MHS ([01:07:06](#)):

(silence)

James Valentine, JD, MHS ([01:07:13](#)):

We'll give you a few more moments here to get your responses in. It looks like we have good representation across most of the U.S. time zones with the largest representation being from a U.S. Eastern Time. But, we do have a good representation across U.S. Central, Mountain, and Pacific Time zones. We do have some participants from Europe, the Middle East, and Canada, as well as other regions not listed on this slide.

James Valentine, JD, MHS ([01:07:42](#)):

We can move to our third polling question. So here, the question is, are you or your loved one with hearing loss, either A: female, B: male, C: non-binary, or D: prefer not to identify. So again, if you're a caregiver, please answer on behalf of the person with hearing loss, for whom you care.

James Valentine, JD, MHS ([01:08:07](#)):

(silence).

James Valentine, JD, MHS ([01:08:25](#)):

We'll give you a few more moments here. So, it looks like we're seeing a little bit of a consistent split here. About 60% of our participants with hearing loss are female, and about 40% are male. And then we see, we do have participants with hearing loss that are non-binary or the person for whom our caregiver is cares is non-binary. We're seeing a little bit of responses coming in here. We just want to make sure we capture everybody.

James Valentine, JD, MHS ([01:09:10](#)):

Okay, so if we can move to our fourth polling question. Here, we want to know how old are you or your loved one that you care for with hearing loss? The options are A: 18 to 30 years of age, B: 31 to 50 years of age, C: 51 to 60 years of age, D: 61 to 70 years of age, or E: 71 years of age or older. So, how old are you or your loved one with hearing loss currently. [inaudible 01:09:50]

Barbara Kelley ([01:09:49](#)):

James, that's very representative. You see, we have the most in 71 years of age or older, where the incidence of hearing loss is probably the highest.

James Valentine, JD, MHS ([01:09:59](#)):

Mm-hmm (affirmative). But, great to see that we do have representation today across all of these age ranges. We're very interested to hear from you when you share live later in the meeting what is the cause of your hearing loss that we may see different patterns across the different age groups. So, we want to make sure we hear from all different age groups throughout the session today. So, as Barbara mentioned, as it stands, we're seeing about a third, a little over a third of our participants today,

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71 years of age or older, but we're seeing just over or under 20% for each of the middle age ranges, 30 to 50, 51 to 60, and 61 to 70. And, we do have some participants, about just under 5%, that are living with hearing loss from aged 18 to 30.

James Valentine, JD, MHS ([01:10:59](#)):

If we go to our next polling question. So, now we want to know about what was the age that you or your loved one first have symptoms of hearing loss. And so here, our options are A: birth to 18, B: 19 to 30 years of age, C: 31 to 50 years of age, D: 51 to 60 years of age, E: 61 to 70 years of age, or F: if your first symptoms of hearing loss where at age 71 years of age or older.

James Valentine, JD, MHS ([01:11:32](#)):

(silence)

Barbara Kelley ([01:11:40](#)):

James, it looks like we have a really good representation from all the age groups.

James Valentine, JD, MHS ([01:11:46](#)):

Yes, we're seeing a shift here from the last polling question that we had, where it was shifted to the older age ranges. Here, you're seeing that many of those people clearly have been living with hearing loss since a very young age, with about 40% of our participants having had their first symptoms of hearing loss in childhood. But we do see again, a good representation across all age ranges of first symptoms of hearing loss being all throughout life.

James Valentine, JD, MHS ([01:12:20](#)):

We go to our sixth polling question. So here, we want to know a little bit about your hearing loss. Is it A: in the right ear, B: in the left ear, or C: in both ears?

James Valentine, JD, MHS ([01:12:33](#)):

(silence)

James Valentine, JD, MHS ([01:12:46](#)):

So, we'll give few moments here. I promise these polling questions will be a little harder to answer, will require a little bit more thought later in the program. But again, we really want to get a sense of who is in our audience, who we have represented today. So, we're seeing that we have a very high percentage of our individuals represented today with hearing loss in both ears. We do see some unilateral hearing loss from people living with hearing loss in their right ear. At this time, it doesn't appear we have anyone who only has hearing loss only in their left ear. Okay. Oh, and that just changed, always getting more responses trickling in. So, we do have a few people, a handful of people in each of only the right ear or the left ear. So again, we'll be interested to hear about the causes of hearing loss, how that's differed based off of whether you have hearing loss in one ear or both ears, throughout the program today.

James Valentine, JD, MHS ([01:13:50](#)):

And so if we go to our last polling question, we want to know here, what form of hearing loss do you or your loved one have? So, we'll start to get a sense of this question that I've been mentioning. We have

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A: sudden onset, B: genetically-based or hereditary, C: post head or ear trauma, D: post loud noise exposure, E: medication that was toxic to the ear, F: after a disease or virus, G: autoimmune disease, H: Meniere's disease, I: from a tumor, J: from aging, K: if you were unable to determine the cause, or L: if you're unsure of the cause. We'll give you a minute.

Barbara Kelley ([01:14:45](#)):

James, many times, the determination of hearing loss is unknown.

James Valentine, JD, MHS ([01:14:50](#)):

Mm-hmm (affirmative).

Barbara Kelley ([01:14:50](#)):

So I'm seeing factors K and L being on top, not a surprise.

James Valentine, JD, MHS ([01:15:01](#)):

We're seeing quite, at least relative to others, about a third of the population with genetically-based or hereditary hearing loss. So, that's by far the greatest representative group of individuals with hearing loss. And then after that, for those who do know the cause, we see a good distribution, perhaps the second is after a disease or virus. We see kind of tied in about third being sudden onset, after a loud noise exposure, and due to aging. But again, we're seeing a representation here across everything. And, we don't see as a hearing loss as a result of medication that was toxic to the ear.

Barbara Kelley ([01:15:44](#)):

And that's interesting, James. We do have somebody among our panelists, who will relate to the question on medication that was toxic to the ear after chemotherapy.

James Valentine, JD, MHS ([01:15:56](#)):

Mm-hmm (affirmative). So, thank-you for everyone for completing the first set of polling questions today, and bearing with us through that. I know it's very important to get a sense of who we had represented. So now, we get to move to the most important part of today, which is really where we get to start hearing directly from you, individuals living with hearing loss and direct caregivers. And, we're going to go into that first topic that I mentioned. And so, if we can show our session one discussion questions. These are what we'll be exploring with a panel discussion, and then opening it up to all of you in the audience to help answer. And so, here in this first session, we really want to understand what it is to live with hearing loss. We want to explore the symptoms and health effects that are a consequence of your hearing loss, and those that have the most significant impact on you or your loved one's life.

James Valentine, JD, MHS ([01:16:55](#)):

We're going to want to explore how hearing loss and the symptoms related to it might vary, whether that be from day to day or in how they change over time, whether that be week to week, month to month, or over the course of years. We're going to be asking you not only to help describe and help us understand what those symptoms and health effects are, but also help us understand how they impact your life, including important activities in your life that maybe you can't do at all, or as fully because of your hearing loss and associated symptoms. And then, knowing that not all of the manifestations of your

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hearing loss and the symptoms are things that you've already experienced, but maybe things that will come in the future, we want to explore any fears, worries, concerns you have for the future living with hearing loss. So, to get us started on this topic, we have a panel of members of this community who are going to be sharing their experiences of living with hearing loss. We have Roxana, Tim, Catherine, Anna, and Jake. So Roxana, why don't you take it away?

Roxana ([01:18:07](#)):

I'm Roxana Rotundo born in Venezuela, lived most of my life in the United States, and the recipient of two cochlear implants. We refer to them as CIs. This is my story before I did my CIs. My hearing loss started when I was 25 years old. At the beginning, it was only on the high frequency sounds. So, women's voices were harder to understand than men's. With time, the loss started getting worse. I was diagnosed with a progressive hearing loss caused by an unknown autoimmune disease. At that time, I started my own business, a company that distributes films and TV show to Hispanic TV networks. I was doing very well. The first challenge I noticed was how some things became very hard to understand. I noticed how, for example, people from Peru and Chile were very hard for me to follow. With time, things started to get worse, and what is called a drop in my hearing aesthetic to be more noticeable for me.

Roxana ([01:19:12](#)):

I always say it's like a mourning process. Every time you have a drop, you need to mourn that loss. And for some days, you will feel very sad and shocked because you know it will get worse. I was a young woman entrepreneur, being successful in a man-dominated industry, and it was not easy to offset my hearing loss in this environment. I buy films in movie festivals around the world, and the screening of the movies in the events without closed captions was starting to be almost impossible. I started to ask for the script before the presentation of the film so it will be easier for me to follow. But, what was harder for me was the impact on the negotiation process. The biggest part of my job is negotiating the films in those [inaudible 01:20:02] and who I was negotiating with. It started to become harder and harder depending on the tone of his or her voice.

Roxana ([01:20:12](#)):

When I decided to tell a few people about my hearing loss, some people took advantage in negotiating meetings, saying they will tell me things that they did not. Because something that you notice when you lose your hearing is that you know when you hear well something, and when you don't. I hid my hearing loss for a very long time. And let me tell you, it's exhausting. I started doing my business by email, and that never can be the same. My social life start being dominated by my hearing loss. I stopped going out with friends that were hard for me to understand, but at the time you don't realize it.

Roxana ([01:20:51](#)):

Although I'm bilingual, I prefer to speak Spanish because Spanish is a language that has less high-frequency sounds are more syllables on their words. And therefore, it was easier for me to understand than English. This English accent that you're hearing, I did not have it on my twenties. When I see friends of my youth, they are very short to hear my new accent. I'm part of a new study now in the University of Miami, that distributes how a person completely bilingual can still have better results in the hearing test in Spanish, even if Spanish is that person's second language. There is a huge self-stigma with hearing loss. It's not easy when you operate a hundred percent in the hearing world to tell someone you don't

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hear well. And also, to show your hearing aids. Hearing loss involves contents loss. When you are a cochlear implant candidate and have the courage to get the implant, they tell you there is a very high probability you will lose that little remaining hearing you have in the surgery. That impacted my decision to get a CI for many years. I wanted to hold to that little remaining hearing for some time. Although in practical life, it was not useful. But it was mine, and it was so hard to let it go. I had my first CI three years ago and the second one a year ago. And here I am, after a lot of work, in what I call the miracle of hearing back.

Roxana ([01:22:25](#)):

There is so much information to share. Hearing loss is called the invisible disability because no one seeing you knows you have hearing loss. Even though I'm hearing all of you now, I'm deaf. If I take out my two processors, I hear nothing. So, it's complicated for many to understand. The process is really scary, especially if you are alone and don't know anyone with hearing loss. That is why I just finished a documentary called, "We Hear You," about my hearing loss experience and experiences of three friends. I will advocate as much as I can because there is so much work to be done. Thank you for hearing my story.

Tim ([01:23:10](#)):

Hello everyone. My name is Tim Browning. My hearing loss journey started at birth. My parents thought I was such a nice, quiet baby with a tendency to get scared easily. It wasn't until I was four that I was diagnosed with moderate bilateral hearing loss. I was fitted with my first hearing aid with a long cord from my ear down to a neck pocket hearing aid holder. As you can guess, I went through a difficult stretch to catch up, starting with special education for children with hearing loss. It was there where I began learning how to speak, listen, and communicate. I started Kindergarten at a regular school. And at first I thought, how cool was it to show off my hearing thing gadget to my classmates. But as we got older, I started to realize the struggle to communicate with my classmates. My speaking vocabulary was limited, I missed words spoken to me, and I struggled to understand and just keep up.

Tim ([01:24:10](#)):

I felt inferior, and my classmates treated me as such because they didn't know better. Teasing, mocking, how I talked, and bullying was a daily experience for me. It was difficult even to the point that I would keep track of how many summer vacation days were left before I had to return to school. You see, for me, it's not just hearing loss, but communication loss. I sounded off because I couldn't speak what I couldn't hear. I would misspeak words that had S, B, C, D, T, H, in them all the time. I would continue speech therapy throughout high school, but it only did some much. Being withdrawn and quiet with my coping mechanism, but it didn't save me from low self-esteem issues and isolation. I carried these struggles throughout my school life, doing everything I could to hide my hearing loss, keeping my hair long over my ear, pretending to understand the smile, and even going to school without my hearing aid. But, it didn't stop the anxiety and fear of hearing loss related embarrassment.

Tim ([01:25:16](#)):

Teachers tried to help, but they simply didn't understand hearing loss in terms of the emotional and mental toll it took on me. Sitting me in front of the class wasn't always the answer because hearing loss includes other internal struggles. Dating for me was defeating. While guys had stylish haircuts, I continued to cover my hearing loss with what I call an outdated seventies' haircut that won't go away.

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Not only did I look out of fashion, speaking on the phone was torture. Could I focus well enough to understand? But also, imagined the voice on the other end noting my voice sounds a little funny. Like something is not quite right with me because I'm mispronouncing words. I cannot hide it on the phone, so I just never could let go and just be myself.

Tim ([01:26:07](#)):

Working in the corporate world after I finished school, I had success, but at the price. I worried for days before speaking in front of people, for fear could I understand if they ask me questions? What do I say in a meeting when my soft spoken manager is asking me for advice? How in the world do I handle this conference call with people with thick accents? I can't tell you how exhausted I would feel afterwards, only see my work associates on their merry way, filled with energy. I could have advocated for myself, but I didn't feel comfortable, nor did I know better. I just dealt with it. Today, my hearing loss is now moderate-to-severe. So, it takes a lot of mental energy for me to hear. Getting older, I find fatigue settles in more intensely. I can't enjoy my family and friends quite as much as I used to because I need more time to reset. It's sad to me, but Zoom gathering, talking on the phone, and social media just wears me out faster. I feel upset and frustrated because I can't seem to build the hearing endurance.

Tim ([01:27:16](#)):

Even worse, I sometimes just don't realize how hearing fatigued I am, and how it sets me indirectly down a road of despair without realizing it. I have fears about the future. Dementia and hearing loss seems to show a strong correlation. Will I lose my memory? My mind? If I get more fatigued due to my hearing loss, how can I find the energy to keep my mind sharp? I can advocate, but some days I find that I just don't have the energy. It takes mental and emotional energy to ask people to speak up, talk slower, or show patience with me. And then, they forget. Sometimes I realize I just check out with my hearing environment too overwhelming. And, my tinnitus is getting worse as my hearing gets worse. I have no comprehension of what having a quiet moment in my head sounds like. I hate to say this, but it feels like a dark cloud hanging over me that just won't go away, so it's all I can do to just accept the situation and do the best I can.

Tim ([01:28:22](#)):

I worry that the future won't properly represent the hearing loss community and me. Why have the accommodations at the airport, entertainment, venues, and hospitals to understand, comprehend, and make sound decisions even if I'm too tired to advocate? If new assistive technologies and awareness in the hearing community for my needs are not adequately in place and understood, will it just be too easy for me to isolate and feel hopeless?

Katherine ([01:28:54](#)):

My name is Katherine Bouton. I lost my hearing when I was 30. I woke up one morning and found I was deaf in my left ear. I was also hypersensitive to noise, and I flinched at any kind of clatter. At first, I was frightened, but I was thoroughly tested and nothing was found. I decided I could live with it. I could still hear with my right ear. I didn't get hearing aids. And, the cause was never determined. But over the next 40 years, the loss progressed and it became bilateral. I'm now profoundly deaf in that left ear. And, I have a cochlear implant. I use a hearing aid in my right ear. Neither allows me to hear in any way resembling normal hearing. As my hearing worsened over the years, I went through periods of panic and depression. It took me a long time to learn to live with hearing loss.

Katherine ([01:29:50](#)):

I can hear sound, but I can't distinguish speech. I'm a good speechreader, and this supplements my ability to function, but COVID-19 was an enormous set back. Over the past year, I've been unable to understand anything said by someone wearing a mask. Unfortunately, I spent much of 2020 in hospitals with my husband who was being treated for cancer. His chemotherapy treatments took all day. The chemotherapy suite and open plan to facilitate communication was a nightmare acoustically. The hospital did not have clear masks. I tried using my smartphone captioning app, but the noise in the room drowned out the speaker so that the captions didn't work. It was intensely frustrating not to be able to hear what nurses and doctors were saying. As my husband's caregiver, I worried that I was missing vital information. I also worried that if I asked for us to be moved to a quieter place, or if I asked the nurses to talk to me separately, that I would shift the focus to myself, I would make my needs paramount. The nurses were already overwhelmed and my husband was dying. I explained, but I didn't demand. Sometimes I had to leave the hospital because it was too much for me. Masks will continue to be used in hospitals long after COVID, and unless clear masks become routinely available, I dread having to go back into that situation. Oddly, my best days have also been in the past year. I'm a writer and an advocate for people with hearing loss. Because every meeting was held virtually, I was able to continue working with my committees and groups. I could follow along with captions, either provided by the host or using my phone app. I did the same with social gatherings. I felt more present in the meetings in the past year than ever before in my life. I am not looking forward to the post-COVID-19 world. My hearing friends can't wait till we go back to restaurants and dinner parties, but because it's almost impossible for me to hear speech in noise, that means going back to sitting at a table and smiling because I can't follow a word being said.

Katherine ([01:32:12](#)):

The impact of my hearing loss was also significant. When I was working. I was a newspaper editor and writer. Although I told my department heads that I had hearing loss, they forgot repeatedly. I was expected to attend daily meetings, to have business discussions on the phone, to understand what someone across the room was saying. The stigma of hearing loss is pervasive and hugely damaging. And it is self-fulfilling. I was reluctant to ask for accommodations, and eventually I couldn't do the job anymore. I took early retirement at 62. My employer would have found another position for me, but I wanted the one I had. Self-stigma was at work here. I was too proud to acknowledge my loss, too ashamed to accept a position that would have been an acknowledgement of my disability.

Katherine ([01:33:06](#)):

My biggest concern going forward, now that I'm a widow and living alone, is whether my grown children will trust me with their children. I'm not sure that I would trust me with their children. I worry about this, even though I don't even have grandchildren yet, but I've always wanted to be an active grandparent, a babysitter while their parents work, or to take them on vacations. I'm afraid that my hearing loss may make that too risky. The most frustrating thing about my hearing loss is that despite having the most sophisticated and most expensive devices, I still can't hear. I know that hearing loss is complicated. I know that hearing is complicated, but I still think that hearing devices should work better.

Katherine ([01:33:51](#)):

I'm certain that the stigma associated with hearing loss has delayed serious work on hearing technology until very recently. Even now, for myself, there are times when I want to retreat into isolation rather

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than take the initiatives that would allow me to continue to be an active member of society. But I know that isolation leads to depression, and I know that depression can contribute to dementia. So I push on. I don't want my life to be lost because of the stigma of seeming old and useless. I don't want my life to be lost because I can't hear. Thank you.

Anna W. (01:34:38):

Hello. My name is Anna Westrick. I have genetic, progressive hearing loss in both ears and started wearing hearing aids at the age of 43. I'm the mother of two boys who are 11 and 12 years old, and I work as an anesthesiologist in the community hospital in my town. I also serve in administrative roles in the world of quality and patient safety in my hospital system. Even though I grew up with a mother and a brother who had diagnosed hearing loss, I did not realize I had hearing loss myself until later in life. The first symptom I noticed was tinnitus, or ringing in my ears. Even though it would bother me at night, I still was lucky enough that I could sleep, and usually I just ignored it. But, I actually started to realize that I had hearing loss when I had trouble hearing my youngest son, who has a high pitched voice when we were talking in the car, and he was in the backseat, or when he was calling to me from another room and I couldn't hear him.

Anna W. (01:35:44):

I also noticed I had difficulty in bars and loud restaurants, and I noticed that I had trouble hearing casual conversation while working in the operating room if people weren't facing me, all of these things led me to finally go and get my hearing tested. And, in the audiologist office, I found out that I had severe high-frequency hearing loss. Over the next year, my family had genetic testing and I found out what the autosomal dominant gene was, and I also found out that both of my children had that hearing loss gene. The genetic testing center also provided me with a predictive model for what my hearing loss will look like, and in the future as my disease progressed. My hearing loss impacts me on a daily basis in personal and work situations. While we could still eat in restaurants, I would have a lot of trouble hearing full conversations in the loud restaurant.

Anna W. (01:36:45):

For work meetings, this has resulted in difficult situations where I'm forced to repeatedly ask for my colleagues to repeat themselves and clarify. Socially, loud bars and coffee shops are settings that make casual conversation with friends stressful, even if I'm wearing my hearing aids. This has resulted in some embarrassing misunderstandings, and makes what should be a relaxing night out stressful. At work during in-person meetings, none of the auditoriums and conference rooms where I work are hearing accessible. In the past, because the main speakers were usually mic'd. I could hear them clearly, but questions from committee members or sidebar conversations were very difficult. Now that meetings are all online. It's rare that I find a Zoom meeting or other online platform meeting set up with high-quality, real-time closed captioning or transcription. There may be closed captioning as an automated or free function, but it's often inaccurate. And closed caption that's not accurate, makes it more difficult for me to follow the discussion, as I'm trying to read and listen at the same time and reconcile the two inputs to make sense of what's being discussed.

Anna W. (01:37:58):

So at this time, my best solution is to use noise cancellation headphones and make sure I'm in a quiet environment for all meetings. In my job, I have to wear masks in the operating room. Since the

pandemic. I wear a mask at all times in the hospital. Masks make it even harder for me to understand conversation as the mask covers up non-verbal expression cues and makes lipreading impossible. I've noticed that the masks also make it very difficult for my older patients to hear me. In my job, I have to establish rapport with my patients in a very stressful time right before they're about to undergo a procedure or a surgery. And when they struggled to hear me, it makes us essential connection very challenging to establish. The pandemic has made this health care-related communication problem, even more obvious. And while I know that there are clear masks available, my hospital does not use them for patients or staff with hearing loss at this time. I know my hearing loss is progressive.

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Anna W. (01:39:02):

I know my hearing loss is progressive. The predictive progression model given to me through genetic testing shows a steady decline expected. So far, thankfully, I've not had measurable deterioration in my own hearing. However, I worry about how my hearing loss will impact my ability to communicate with family and friends, as it becomes more severe. I worry that I will have difficulty keeping in touch with my children when they go away to college. I worry that I will have difficulty participating in family reunions and other large loud family gatherings. I hope new technology will become available to address these personal and professional challenges with hearing. And eventually I hope that there's cures for genetic hearing loss when identified.

Jake S. (01:39:52):

My name is Jake and I'm from Cleveland, Ohio. My experience with hearing loss was unfortunately a very sudden and big mistake. And like a lot of people who've made that same mistake. I was completely unaware of the dangers and consequences of damaging my ear. Like most kids, I had zero problems with my ears growing up. It wasn't until I turned 18, when my dad asked me to go on a hunting trip with him out west. I'm not a hunter and I had no interest, but he sort of persuaded me with it being a father and son trip. So I ultimately decided to go with him. On the first day, everyone decided I was going to shoot first. We woke up at three in the morning and it being super early and pitch black outside, we forgot our earplugs. The rifles we were using were very powerful. And while I didn't really think anything significant was going to happen, I vaguely knew that loud sounds were bad for your ears. Everyone in the group told me that, despite not having any earplugs, that I would be totally fine and that nothing bad was going to happen and that I should stop worrying about it. I conceded, thinking they were right and eventually fired the gun.

Jake S. (01:41:07):

The initial blast felt like it smacked the side of my head. My right ear didn't receive any trauma, but my left ear did. Almost immediately after I fired the shot, I knew I had done something very bad. It felt like my ear was numb and I could clearly tell something was wrong. I'd try to play it off like it was fine, like it was only temporary. But after about a day, it became very clear that it wasn't temporary and I had clearly injured myself.

Jake S. (01:41:38):

When I got home, I started to notice something that would quickly become the worst part of my injury. I started having sound sensitivity in my left ear, also known as hyperacusis. I also started experiencing

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tinnitus that was tied in with the hyperacusis. I started to become really worried about what I was experiencing, but I had an ENT appointment the following day after I came home. So I figured that the doctor would fix me up and I'd end up being fine.

Jake S. (01:42:11):

I went to the doctor and explained what happened. I was put through several tests, but ultimately he came in the room and apologized to me and told me that there was really nothing he could do for me. I came home, sat at my kitchen table and put my head down and started sobbing. The gravity of the situation completely emotionally overwhelmed me and I had this realization that my life, as I knew, it was basically over. And this was my new reality.

Jake S. (01:42:44):

Over the years, dealing with the damage to my ear has been somewhat of a process. The symptoms I have experienced have stretched far beyond just the hearing damage and hyperacusis and tinnitus. Nearly a year after my initial injury, I started noticing I was having balance issues. I started developing vertigo, which turned into vestibular migraines, which have basically taken control of my life. My ear sensitivity causes migraines, which in turn makes my ear sensitivity and tinnitus even worse. All of this has caused major strife in my life and has made things much more complicated. Being younger, I almost feel like there's an invisible barrier between me and my social life and people my age. Stuff like going out with your friends, going to noisy restaurants, going to the movies, et cetera, things that no one even really thinks about have become daily battles. And more often than not, I feel isolated from my family and friends. It really feels like I'm sort of watching everyone else live their lives while I'm stuck in place, hoping maybe one day to return to normal life.

James Valentine, JD, MHS (01:44:07):

Well, thank you, Jake. And to all of our panelists for topic one, for sharing your experiences of what it is to live with hearing loss, the symptoms, the impacts on your life. So important for us to hear your stories, your journeys, living with hearing loss. And that's exactly what we want to do now with the broader audience that we have with us live today. So this is my first opportunity to invite you if you'd like to share your experience living with hearing loss, to call in by phone, you can dial in at 1.703.844.3231. Again, that's 1.703.844.3231. We invite you, even if you're using a caption telephone to please call in. We'd be very eager to hear your voices, hear your experiences.

James Valentine, JD, MHS (01:45:01):

But to get us started thinking about this topic of what it is to live with hearing loss, we're going to go back to the polls. So I'll ask you to pull your phone back out, go to that second tab you had open. Go back to [PollEV.com/HLAA](https://www.pollEV.com/HLAA). This is for all of our individuals living with hearing loss and their direct caregivers. Even if you're joining us and weren't able to answer the earlier polling questions, we still would love for you to answer these.

James Valentine, JD, MHS (01:45:29):

So if we can go to our first polling question, we want to know which of the following hearing loss related health concerns do you have, or does your loved one who lives with hearing loss have either currently or have had in the past. And here we want you to select all that apply. The options are A: Trouble hearing with background noise. B: Difficulty hearing higher pitch sounds. C: Sounds that are muffled. D: Issues

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communicating verbally. E: Trouble with balance or vertigo. F: Headaches. G: Difficulty hearing consonants. H: Fatigue. I: Loss of initiative or interest in work or hobbies. J: Social isolation or avoidance. K: Mood changes, things like depression or anxiety. L: Tinnitus. Or M: Some other health concerns or symptoms of your hearing loss that you have had either currently or in the past, or for those of you who are caregivers that your loved one has had. And please select all that apply.

James Valentine, JD, MHS ([01:46:37](#)):

One thing I'll note is that on these polling questions, when we have more than one response option, what you're seeing is a percentage of the total responses. So that does not reflect a percentage of people who selected a particular response. So the easiest way to think about these is kind of bars that are ranking. So we see here first that A: Trouble hearing with background noise is the top selected of these different health concerns. After that it's looking like sounds being muffled, followed by difficulty hearing higher pitched sounds and fatigue, as well as social isolation and avoidance being the next highest. But we really do see quite a range here. Every symptom we listed, being selected. And then also we see other symptoms, response option M: we're seeing other things that we haven't listed. So we want to make sure that we hear about those things as well.

James Valentine, JD, MHS ([01:47:40](#)):

We want to hear about even maybe less common symptoms or health concerns and what those are. So if you can call in, again, you can write in under the live stream with your comments, we'll be reading some of those as well.

James Valentine, JD, MHS ([01:47:56](#)):

So we move to our second polling question. Now we want to know of those same health-related concerns we want here... Now you have to think about what are the top three most troublesome concerns that you have, or have had. So the same response options. I won't reread them all this second time, but you'll see they're the same as from the first polling question. Here, select up to three of those that you view as most troublesome to you or your loved one's life as a result of hearing loss and other associated symptoms.

James Valentine, JD, MHS ([01:48:39](#)):

I promised that these would be a little harder and I'm sure all of these health concerns have impacts on your lives, but here we want you to think and pick those that you think are those that create the most burden or trouble for you in your daily lives.

Barbara Kelley ([01:49:01](#)):

James, I think it's interesting that the top two, one is purely a communication problem. And the second one is a psychosocial problem, the social isolation or avoidance.

James Valentine, JD, MHS ([01:49:15](#)):

Yes. And I think it will be really important for us to hear from those of you calling in, writing in, how some of these more direct symptoms actually do impact some of those bigger picture or more downstream issues like social isolation and avoidance. I would guess that there's a relationship between A and J here and that we'll be hearing about. But we'll give you a couple more moments here to get your

responses in. We're seeing those as the highest. After that, we're seeing a cluster of difficulty hearing higher pitched voices, sounds being muffled, issues communicating verbally, and fatigue kind of as the grouping of third most troublesome symptoms.

Barbara Kelley ([01:50:06](#)):

And it's no surprise James, because we hear this daily—the trouble with hearing and background noise. And that has come up on top on both of the polling questions.

James Valentine, JD, MHS ([01:50:16](#)):

Yes. And I think what we've heard already, some of that from our panelists and looking forward to, even on some of these more common experiences, they impact everybody differently. And so we'd love to hear your personal experience with how some of these symptoms impact your lives because everybody is at a different point in their life. We're all individuals. So we really want to hear about those individual impacts.

James Valentine, JD, MHS ([01:50:49](#)):

So to get us started on that, I want to welcome our Zoom discussion starters. Here's a grouping of other members of your community here who are going to be starting us off. Just another reminder that you can dial in at 1.703.844.3231 at any time. We'd love to get you into the queue, we'd love to hear from you directly.

James Valentine, JD, MHS ([01:51:13](#)):

But now let's take it to our Zoom discussions here. So thinking about those polling questions and the different health concerns, but more importantly, that I think harder question of what are the three that are most troublesome for you? Maybe Latisha, you can start us off. When you were looking at that polling question, what were you thinking? Or just generally, what are the top concerns related to your hearing loss?

Latisha ([01:51:49](#)):

Hi, everyone. I'm Latisha, and I was born with sensorineural hearing loss, but I didn't know until I was 19 years old because my mom passed away when I was six weeks old. And my mother's mother and my father had hearing loss. So in a household of six of us and growing up during the seventies, it wasn't detected that I had hearing loss. So currently I'm a paralegal at Seton Hall Law School. I've been here for 30 years and because of the pandemic, I finally was placed in a position where my skills can really be utilized. And I graduate in a couple of months, I'm receiving my PhD in philosophy, organizational development and leadership. I wear two behind-the-ear hearing aids. And without my hearing aids, I can't hear anything. So I read lips all the time and I need captions at all times.

James Valentine, JD, MHS ([01:52:52](#)):

So Latisha, what would you say if you had to pick one symptom or health concern related to your hearing loss that has the biggest impact on your daily life? What would that be?

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Latisha ([01:53:04](#)):

Okay. Background noise is a really big issue for me because I can't hear speech with background noise. And when a siren goes through my house, it's just too loud. And I'll ask my husband "is that very loud to you?" But he'll say, "it's loud, but not the way I hear it." And then at the airport, any place in public, I can't hear speech without reading lips. And noise, it just blocks out any type of speech whatsoever. It's frustrating. It causes fatigue. It makes me tired. And it's difficult because without reading lips, I really don't understand. I just hear sound and noise and background noise makes it even harder for me to hear speech.

James Valentine, JD, MHS ([01:53:54](#)):

And you mentioned that you are a paralegal and also working on your Ph.D. How has this particular symptom... Congratulations by the way on graduating here soon. But how does this particular symptom, this background noise, how has that impacted your ability to work and go to school?

Latisha ([01:54:19](#)):

Well, actually one of the biggest reasonable accommodations I was given at work, I was placed in a quiet area to work. So I don't really hear noise in the area where I work. And emailing, texting, that helps. If there are group conversations, I can't follow them. Only talk to the person who's standing right next to me. I miss all of what's going on at meetings, unless I'm reading something. But in a regular meeting without the digital platform, I can't hear speech and follow what's happening in meetings. So a lot of times I'm sort of excluded from meetings like that. But now I'm involved because of what's happening with the pandemic.

James Valentine, JD, MHS ([01:55:03](#)):

Sure. Thank you so much, Latisha.

Latisha ([01:55:05](#)):

Thank you.

James Valentine, JD, MHS ([01:55:06](#)):

Tony, how about you. When you were thinking about that polling question and having to pick the top health concerns related to your hearing loss. What kind of came to mind for you?

Tony ([01:55:21](#)):

Yeah, I'm Tony from Westland, Michigan, a suburb of Detroit. I was born with a hearing loss, mild at first, sensorineural. It's hereditary on my father's side. So I have a sister with hearing loss and a brother that has normal hearing.

Tony ([01:55:41](#)):

Anyway, as far as the symptoms, what's bothering me the most now, as an adult, is the fact that sometimes because I don't hear all the conversations, it's kind of hard and difficult to ask a question and even answer a question because there have been times when I've answered the wrong question, because the brain didn't put it together, right? Right. And so, I'm answering the wrong question and of course people think you're aloof because it happened. And then I realized people starting to smile,

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laugh. And so I kind of like withdraw. And so then other things is when somebody will say something, you don't hear it. And so a little bit later in the conversation, I may ask a question. I'll say, "well, what do you think about...?" And somebody will say, "we already talked about that." So it's very embarrassing. And so again, you tend to get more isolated when that kind of happens. So then it's the part where now I'm totally avoiding a lot of situations.

James Valentine, JD, MHS ([01:56:54](#)):

Sure. Do you notice anything that makes that kind of conversational hearing better or worse?

Tony ([01:57:05](#)):

Well, certainly the technology has improved enough, so my hearing aids do have some directionality control. So the technology has helped and I now have a remote microphone, so if it's not too off awful noisy, the remote microphone seems to help quite a bit. So yes, there has been some help with technology.

James Valentine, JD, MHS ([01:57:29](#)):

Sure. Thank you so much for sharing that Tony as well. I see we have caller, Joy from California, who wants to speak and share some of her experiences of living with hearing loss and some of the impacts it's had on her and her family. So Joy, this is James. I'd like to welcome you to the show.

James Valentine, JD, MHS ([01:57:57](#)):

Joy, are you with us?

Joy ([01:58:02](#)):

Hi, can you hear me now?

James Valentine, JD, MHS ([01:58:04](#)):

I can. Welcome.

Joy ([01:58:07](#)):

Hi, thank you. So my experience has been, I have a genetic disease that leads to progressive hearing loss. It was inherited from my mom and affected my uncle and my sister, my son. And I have high frequency hearing loss and peritonitis.

Joy ([01:58:28](#)):

And my problems day-to-day are very social in nature. Because I'm a mother of three children and of course I live in a community of hearing people. So hearing other mothers in social settings for their sports or their school is extremely challenging. And then frankly, honestly, I have a very difficult time hearing my son. He tends to be more soft-spoken and he has kind of speech issues. He doesn't speak very clearly or very concisely. He takes awhile to put his thoughts together and between his speech communication problems and my hearing problems, it's a big fat roadblock for us. And it's frustrating, mostly because I'm trying so hard not to let my hearing loss be known to him, although he knows it, but I don't want him to see it as a burden because if I know that he'll be getting the same hearing loss. So it adds that extra element of guilt and frustration for both of us.

James Valentine, JD, MHS ([01:59:41](#)):

Wow. Yeah. Thank you for sharing that, Joy. And you mentioned you have tinnitus that comes along with your hearing loss. When you are, whether it's having trouble hearing your son, like you just described. Can you maybe help us understand how much you might attribute that to the difficulty of hearing and maybe how does the tinnitus play into that or compound that?

Joy ([02:00:11](#)):

So, sorry. Again, it's the whole hearing and understanding at the same time thing. But I think the difficulty in hearing him is the biggest aspect of our communication lapse. Because he'll tell me something and it takes me awhile to know what he just said, or I get bits and pieces of it, but not the whole thing. And then I ask him to repeat, and of course he gets frustrated. He's a preteen, so he gets very frustrated with me asking him to repeat himself. But I have to get him to repeat himself several times because I want him to understand the importance of communicating clearly. And that even though it's a burden for him to repeat himself, it's important that he makes sure that his statement is heard. So it's stressful.

James Valentine, JD, MHS ([02:01:10](#)):

Sure. And that's very helpful. That's exactly what I was curious about. So thank you so much Joy for calling in and sharing your and your family's story.

James Valentine, JD, MHS ([02:01:23](#)):

I see we have another caller who wants to speak about difficulties resulting from their hearing loss. This is Phyllis from Baltimore, Maryland. And so I'd like to welcome Phyllis to the show, Phyllis.

Phyllis ([02:01:44](#)):

Nope.

James Valentine, JD, MHS ([02:01:46](#)):

Hi, Phyllis. Are you with us?

Phyllis ([02:01:49](#)):

Hi. Yes.

James Valentine, JD, MHS ([02:01:51](#)):

Welcome. I'd love to hear a bit about the experiences...

Phyllis ([02:01:54](#)):

I'm sorry. Can you repeat that?

James Valentine, JD, MHS ([02:01:57](#)):

Yes. Just welcome. Would love to hear what you wanted to share.

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Phyllis (02:02:03):

Say it again, I'm sorry.

James Valentine, JD, MHS (02:02:05):

No problem. Just welcome and please share what you called in to share.

Phyllis (02:02:12):

I'm just having a lot of trouble hearing you. I'm sorry.

James Valentine, JD, MHS (02:02:17):

No need to be sorry. I'm just very interested in what symptoms and health concerns you wanted to talk about.

Barbara Kelley (02:02:32):

I think James, we're seeing the problem firsthand here.

James Valentine, JD, MHS (02:02:35):

Absolutely.

Barbara Kelley (02:02:35):

And Phyllis is terrific to try to call in. She's apologizing for hearing loss. Did you notice that? There's just absolutely no need to apologize, Phyllis. So, if you can still share what you want to share, please go ahead.

Phyllis (02:02:53):

Can you repeat that please?

Barbara Kelley (02:02:55):

Phyllis, could you please go ahead and share what you would like to share with us? We're ready to listen.

Phyllis (02:03:02):

Okay. Very good. Thank you. First of all, I appreciate this very very much. It's very, very interesting hearing from a different kind of perspective. When it came to listing the three things that were most difficult for us in terms of hearing, I had to check other as one of mine, because you did not have it listed that that one has difficulty hearing voices in the lower register. The most common hearing loss is voices in the higher register. However, even though I have a little bit of difficulty with voices in the lower register, excuse me, the higher register, my most challenging hearing problem is hearing voices in the low register. That means I cannot hear most men. I have great difficulty hearing anyone in my family who is a man, like my husband, my brother-in-law, my grown grandchildren, et cetera, et cetera.

Phyllis ([02:04:26](#)):

That is my real challenge. And the challenge is enough that I have had to withdraw from all kinds of group activities because it's very, very hard to hear. I remember when I got my first hearing aid that the audiologist was very excited to hear what my outcome was. And I said to her that the thing that I hear the best of all is my refrigerator. What I was hearing louder than anything with what she had given me was the what's the hum of the refrigerator. And that was certainly not a good adjustment at all.

Phyllis ([02:05:20](#)):

Nobody has ever been able to come up with what I can do to hear the lower register voices. I have tried many, many different hearing aids, different brands, and they all seem not to be able to help. So I'm hoping that perhaps at some point, people who are out there who are looking for a challenge in terms of improving the future for others. I know I'm probably part of a small group that has this problem, but somehow to figure out how to help people who have lack of ability to hear voices in the low register would be incredible. Thank you very, very much for listening and I'm looking forward to the future.

James Valentine, JD, MHS ([02:06:30](#)):

Well, thank you so much for sharing, Phyllis, and thanks for bearing with us so we could really hear that important testimony.

James Valentine, JD, MHS ([02:06:38](#)):

I see we've been getting a lot of written comments coming in as well. So, want to encourage you to keep sending those in to that comment box that you see under the live stream. But now I want to check in with Barbara to see what we're hearing.

Barbara Kelley ([02:06:51](#)):

We do have a lot of written comments and they are broken up into two groups, the communication ones, and then the psychosocial, which is no surprise. We saw that on the demographic polling and we're hearing it from our panelists today.

Barbara Kelley ([02:07:06](#)):

Roz from Laguna Woods, California, says, "I sometimes mishear certain consonants, which causes my mind to wander off, to consider the words I think I heard." Mary from Portland, Oregon, says, "I have difficulty hearing people with masks on, I'm continually missing the punchline or the most important part of the communication." That's, more of the communication, but we certainly have the psychosocial aspects. John from Columbus, says, "I have given up several hobbies because even with considerable hearing protection present, the activity still aggravates, both the pain, hyperacusis and tinnitus too much." And Alexandra from Canada, says, "I am afraid every day of a worsening of my hearing loss and have to withdraw from many social activities that people my age engage in parties, concerts, things like that."

James Valentine, JD, MHS ([02:08:10](#)):

Sure. Thank you, Barbara. And thanks to each of you who wrote in and shared those comments.

James Valentine, JD, MHS ([02:08:16](#)):

I want to check back in with our Zoom panel and see if we have any experiences for symptoms that we haven't heard about yet in part of this discussion. Just give me a little wave of a hand if you have something else to share that we haven't talked about yet, or maybe you have a unique take on a particular symptom.

James Valentine, JD, MHS ([02:08:38](#)):

All right, we'll do Kim and then we'll go to Ron. So Kim, can you start?

Kim ([02:08:44](#)):

Sure. Good morning. My name is Kim Hull and I'm in Washington D.C. And I've been living with hearing loss for probably about 25 years now. And what I think is unique about my hearing loss is that I suffer from Meniere's disease. So it's been a gradual hearing loss early on. And one of the things that I would say that is kind of unique is because the hearing loss fluctuates. So in the beginning, it was kind of not noticeable at one point, and it became gradual. So I would say some of the symptoms that I feel that are unique are fatigue. For me, with struggling to hear all of the sounds around me sometimes ends up with me being fatigued before the day's end, if you will. And it also has a vestibular component too, because the vertigo and balance issues are then mixed in with that.

Kim ([02:09:48](#)):

So my hearing loss has been gradual, but now it's to the point where it's very much deteriorated. It's a one-sided hearing loss. So that's a challenge in itself, particularly when you start to think about devices. So I've used different devices. So I consider my situation very out of the realm of just straight hearing loss, because I am starting to see it gradually worsen and worsen and worsen and trying to compensate is a challenge as well. And I certainly identified with pretty much all of the symptoms that were on the polling. I can say at one time or another, I have experienced some more than others because of the nature of Meniere's. So I just wanted to share that.

James Valentine, JD, MHS ([02:10:43](#)):

Yeah. Thank you, Kim. And you mentioned that you noticed that it's getting worse and worse over time. Can you give me an example of how you can tell or notice that it's getting worse?

Latisha ([02:10:55](#)):

Well, when I visit with my audiologist and the testing shows it, that's one way. And then I can also tell with the tinnitus too. Sometimes it's really up there in decibel, if you will, and then sometimes it'll come back down. But again, that's very characteristic of Meniere's, so it fluctuates a lot, but I've gotten to the point now and I've dealt with them for so long I can kind of establish and kind of know what that fluctuation means. Sometimes it can mean a vertigo attack is about to occur, or sometimes it could mean that I'm fatigued and I just kind of need to tone it down a little bit, rest, and then the hearing will then kind of, I don't want to say normalize, but for me it would normalize. So that's kind of my measure, if you will.

James Valentine, JD, MHS ([02:11:53](#)):

Sure. And do you notice this as an increase in the frequency of these more severe tinnitus and potentially vertigo

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James Valentine, JD, MHS ([02:12:02](#)):

Of these more severe tinnitus and potentially vertigo attacks. Is it happening more days in a given week or a given month?

Kim ([02:12:13](#)):

Yes. It seems to be lifestyle, it just depends if you're rested and you're doing the things you're supposed to do to manage your Meniere's, then that can have an effect on the tinnitus and your hearing overall. But it's not like I have total control over that because it can just be reactive in its own right. Kind of it'll fluctuate on its own and you just don't know.

James Valentine, JD, MHS ([02:12:48](#)):

Sure. Thank you.

Kim ([02:12:49](#)):

If that answers your question... yeah.

James Valentine, JD, MHS ([02:12:50](#)):

It does, yes.

Kim ([02:12:51](#)):

Okay.

James Valentine, JD, MHS ([02:12:52](#)):

Thank you, Kim. Ron, what other symptoms did you want to talk about?

Ron ([02:12:58](#)):

Well, I have some similar experiences to all of the previous speakers, but I think I'm a little different in the sense that I don't know exactly what caused my hearing loss. In 1967, while in Vietnam, I stepped on a booby trap and I ended up losing a leg, but I didn't have any problems other than the principle from that.

Ron ([02:13:22](#)):

I didn't start having hearing problems until 1998. By the way, my name is Ron and I'm from Montgomery County, Maryland, right outside of D.C. But anyway, I started having problems in 1998 and I was diagnosed with Meniere's and I saw my hearing go ... decline over a period of the last 20, 23 years. And every time I would have a severe case of vertigo, it would knock me out for 14, 16, 18 hours. Literally I

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would be unconscious for a good bit of that time and the time that I was conscious I wasn't able to really do anything. I just was like a wet noodle, just lying there in bed.

Ron ([02:14:10](#)):

And each time I would have an episode, I noticed that there was a decline in my hearing. So I, the VA has recognized my hearing loss as being related to the acoustical trauma based on stepping on the landmine in 1967. What I find interesting, it took 21 years for my hearing loss to progress coincidental with the onset of the Meniere's. And I've talked to different neurologists who say there's no conclusive evidence that Meniere's causes hearing loss. And I've talked to people who have had hearing loss that is directly related to Meniere's.

Ron ([02:14:50](#)):

My biggest frustration is it's two things really. One is I can hear, I hear noise all the time. I just don't understand the words. So that's very, very frustrating. And I have two grandchildren. One is 13 and one is seven. 13 year old a boy, he speaks very softly and I have a hard time hearing him. My granddaughter she's seven. And she talks too fast and she talks very loud. Fortunately for me, my wife is usually around me when I'm around the grandchildren. So if I have need interpretation, my wife is my interpreter. And the same thing with social outings up before the COVID, I would very rarely go anywhere without my wife, unless it was a business meeting. I'm semi-retired, but doing a little bit of consulting work and very involved in the disability world, I'm on a couple of nonprofit boards and a couple of the nonprofit advisory councils. So yeah, it's just something that you cope with.

Kim ([02:15:55](#)):

Yeah.

James Valentine, JD, MHS ([02:15:56](#)):

Yeah. Thank you so much, Ron, for sharing all of that. So now I want to take us to kind of broaden this discussion a bit and think about not only what are these symptoms and health concerns that you've experienced, but how have those impacted your daily life. And we have another polling question to help us with this. So pull your phones back out, open that tab in your browser, go to [Pollev.com/HLAA](https://pollev.com/HLAA). And we're going to go to a single polling question here in just a moment.

James Valentine, JD, MHS ([02:16:29](#)):

So the question is, what specific activities of daily life are most important to you that you are not able to do, or you struggle with due to your hearing loss and associated symptoms? And here please select the top three that are most important to you that you are not able to do, or that you struggle with as a result of your hearing loss. The options are A: Participating in social events, B: Participating in sports and recreational activities, C: Attending school or work D: Interacting with family members, E: Attending concerts and events, or F: Some other activity in your daily life that's important to you that you're not able to do either at all, or you struggle to do as a result of your hearing loss. And again, please select those top three activities that are impacted. So we'll give you a few moments here to think about this and answer this question as it stands. It's looking like the top ranked choice is A. Participating in social events. Although we're seeing all of these different selections are in the top three for good proportions of our participants today. We're seeing that attending concerts and events and interacting with family members are both also perhaps kind of the second choice, top choice followed by participating in sports

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and recreational activities and attending work in school, but we're seeing quite a bit of other. So again, we would really encourage you to call in, provide written comments using that comment form. So that way we can understand how any of these have actually personally impacted you. There's lots of different social events, lots of different impacts with family members, and then of course, these other things,

Barbara Kelley ([02:18:39](#)):

James, I'm seeing on the questions that are coming in, that people withdrawing from social events is very high on the list, which tracks with this polling here, and really, basically, that's life. You know, it's relationships with people that make our lives full and hearing loss really cut you off from people.

James Valentine, JD, MHS ([02:19:00](#)):

Yeah. Any particular comments you want to share to that on that note?

Barbara Kelley ([02:19:04](#)):

Sure. I have someone here from Monroe, Texas "I'm 85 and I have age-related hearing loss. I know people who I have been with who are friends, they're pulling away from me and avoiding me because I can't hear what they're saying." This is just so typical. I have another one from Joy, from San Clemente, California." No one wants to feel burdened or perceived as stupid. So as a person who is hard of hearing, I tend to self-isolate at times, especially with people that don't know me well or understand my needs. 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 or glasses with the hearing aids all competing for the ear space. So that's good input on the device side, as well as the social isolation.

James Valentine, JD, MHS ([02:20:03](#)):

Absolutely. And thank you again to those writing in we're going to keep those coming. We'll keep reading those out throughout the day. I do see we have some phone callers who want to share more of the impact in their lives. So I'd like to start with Kate in Kalamazoo. Who's a nurse with a hearing loss. So Kate, I'd like to welcome you to the show.

Kate ([02:20:29](#)):

Hi, thank you. And I just want to start out by saying this meeting is absolutely fantastic and it's so appreciated. I found out about it actually several weeks ago while I was exhausting all the resources, both in my state and federal for help with hearing aid assistance. And I just joined the Hearing Loss Association of America this year and it was specifically to be a part of this meeting. So I'm excited to be here. I am 42 and as you said, I'm a nurse and this pandemic has been really hard. I've not been able to be in patient care. So I sit on hospital committees. I started realizing in college that I was having trouble hearing in lecture halls and taking notes. And I was having a little bit of trouble distinguishing words at that time, but I honestly thought it was, I went to a ton of concerts as a teenager and young adult and lots of loud noises.

Kate (02:21:28):

My first hearing test was at 24 and I was surprised to hear that I had a high frequency hearing loss that was actually registrable. And there was no hope at that time for high frequency hearing loss. You know, it was almost 20 years ago. I grew up with a grandfather who wore a hearing aid at 40, because at that time in his life, he felt that one hearing aid was enough. The technology was also very bad and he was in a lot of discomfort most of the time. And he lived to be 97. And he kept that single hearing aid all those years. And at 35, I was diagnosed with a very severe form of Crohn's disease and had to stop working in patient care. I've had 14 surgeries in the last five years. That same year, my hearing loss went from noticeable to quite severe.

Kate (02:22:25):

And I went in for hearing testing, and unfortunately I was diagnosed with a near 50% bilateral hearing loss. And we thought since it was so severe that it was an autoimmune hearing loss because I was also diagnosed with Crohn's at the same time and some other autoimmune issues. So at 35, I went into Phonak behind-the-ear hearing aids. And it was really difficult for me. I had suffered a lot of loss that year. We knew that I wasn't going to be able to have children because of the type of Crohn's I have and it was just a lot of loss. And then to realize that I had this issue and it was also related to my own body attacking me, I just felt like I was failing myself. And when I went into those hearing aids for the first time, I realized that I'm not sure when I stopped hearing the birds chirp.

Kate (02:23:21):

So I felt extremely grateful to have this ability to hear things that I didn't realize I wasn't hearing, but I was also hearing everything else because they were behind my ears. So I was hearing my ... they were competing for space with my glasses, my face masks, the wind. But again, I felt blessed to be able to hear other things. And two years later we learned that my hearing loss wasn't autoimmune, it was actually a genetic defect. And I really related to Anna's story, one of the guest speakers, because I'm not sure what genetic loss she has, but it sounds very similar to mine. And it was passed to me from my grandfather bless his heart, and he had no idea he had it. I had a GJB two gene defect, and it's going to continue to slope for the rest of my life.

Kate (02:24:14):

And it also puts me at risk for increased chances of breast cancer, bladder, and colorectal cancer, which I just never imagined. I'm now followed by a geneticist and I'm screened yearly for those increased cancer risks. And I'm starting to notice in the last year that my hearing was getting worse. So I went in for new hearing testing and it shows that I've lost another 10% of my hearing bilaterally. So this genetic loss is taking about 3% of my hearing a year. And again, I'm 42 and we're getting ready to try and adopt a baby once COVID is over. I want to be able to hear my baby cry. I want to be able to hear my baby talk when they learn. I have needed the top technology, which I am now just currently trying. I'm in a loaner pair of inner ear Signia silk X hearing aids, and they are absolutely incredible.

Kate (02:25:06):

But one of my biggest problems with having hearing loss at my age, along with the other diseases that I have is I feel completely discriminated against when it comes to the insurance companies. There is a complete lack of any assistance in costs for hearing aids for me, which I will need for the rest of my life. And that's \$6,000 every three to five years, and I need to keep up with the technology so that I can keep

up with my loss. And I'm on Medicare with a very expensive supplemental plan. And I'm unable to qualify for a Medicare advantage plan, which does offer some financial assistance, but it's not for very high tech, good hearing aids. And the reason I can't qualify for a Medicare advantage plan is because they don't cover any of my surgeons for my other specialties and having 14 surgeries over five years, I have a very good team that I've established through five different hospitals.

Kate ([02:26:01](#)):

So the fact that insurance companies don't consider this a medical necessity is very, very difficult for me to understand as a nurse, as a patient, as somebody with a genetic defect. It's like saying you don't need glasses to see, and why do you need teeth in your mouth? You know, hearing is a part of being whole as a person. So I would like to understand when the insurance companies are going to get on board and help people like me. It's very, very discouraging.

James Valentine, JD, MHS ([02:26:34](#)):

Yeah. Thank you so much, Kate, for sharing that. So much frustration that I heard, but also with the progressive hearing loss that you described, so important to understand that, and really also understand your concerns for the future that you mentioned with your hope of adopting a new child and being able to hear that child. So really, really appreciate it. I want to bring it back to our Zoom panel here and explore this topic with Darja. This impacts on activities in your life, things that you maybe aren't able to do or do as fully because of your hearing loss. Darja, what can you share with us on that topic? Darja go ahead.

Darja ([02:27:32](#)):

Oh, yes. I hear sound on my screen. Just now. Can you repeat please? The last question.

James Valentine, JD, MHS ([02:27:42](#)):

Of course. Was just curious on this topic of the activities that have been impacted that are important to you in your daily life. What things are you not able to do or not able to do as fully because of your hearing loss?

Darja ([02:28:01](#)):

Well, first I would like to introduce myself. I'm Darja from Slovenia, from Europe. I am a board member of the European Federation of Hard of Hearing People. And I am really happy that I am today with you and my story's similar as yours, Kate. So I, have progressive hearing loss, now I am deaf and I am using two cochlear implants and the bigger impact on my life is that I was not able to be included in society as I wanted. That was the biggest problem. Even I am a professional therapist by profession and I work with disabled people and I've worked all of my life with professionals in health and social care. I realized that, unfortunately, many people who are professionals and work with disabled people are not able to understand what disability is, in fact, and how that can happen to you. From today to tomorrow, you can have some kind of disability. And for me it's very ... I hardly believe that this so many people are not able to understand that.

James Valentine, JD, MHS ([02:29:44](#)):

Sure.

James Valentine, JD, MHS ([02:29:47](#)):

Is there a particular experience with maybe a family member or a co-worker that have that trouble understanding?

Darja ([02:30:01](#)):

Well, if this, I can say that it's a problem when you've lost your hearing as an adult. And in my case, when I lost my hearing, in fact, I was 23, but that was a progressive hearing loss. And in the beginning, it was okay, the hearing loss. I wore small hearing aids. And of course it was very hard to accept, but at the beginning it was not so hard because I was able to hear almost everything. But, later, I can say now about six, seven years ago, before I got the cochlear implant, it was ... my life was terrible and I was unable to work. I was very, very tired during my job, because it was very hard to work when you are not able to understand and when your co-workers must help you.

Darja ([02:31:10](#)):

And also when the director of our institution decided that I am not so good at my work anymore, but I was, and that was terrible feelings for me. A month ago, I found some description about that. And I was completely down. One day when I read about some article about this, it was not nice feeling. And so also I can say that many times when we, as adults lose our hearing, we must support our family because usually the families don't know nothing about hearing loss. So I lost my humor. I was completely down and there was my children, my mom, my dad, and they didn't know anything about hearing loss. And then I must explain what is going on, but I was completely down. And it was not too fun for me at the beginning...not to find hard of hearing organization, because there is the stigma.

Darja ([02:32:33](#)):

It was stigma to be deaf. I am not deaf. I didn't want to be deaf. And that was a big problem for me. And finally, when I joined that deaf and hard of hearing organization, of course I found some persons with hearing loss, and I can share my experience, my fear, my skills and so on. And they help me very much. So was later on I joined the European Federation for Hard of Hearing People and they helped me again very much. And at the end, when I got the cochlear implant, I can say that my life started again.

James Valentine, JD, MHS ([02:33:23](#)):

Wow. Thank you so much Darja for sharing all of that really the impacts with adult onset hearing loss really appreciate you kind of helping us understand that. I see we have a caller, Ali in San Diego, who has hearing loss that began about two years ago and wants to share his experiences with hearing loss in that time. So Ali, welcome to the show.

Ali ([02:33:53](#)):

Hi James. Thank you. So my hearing loss actually started three years ago. Now that I look back, I unfortunately got the mumps virus three years ago from, I think it was a plane trip from Detroit to LA. I started getting some pain in my ... I didn't know if the mumps initially yes, or getting pain in my ear and then had to go to a hospital and they didn't know what it was. So finally they found out that it was the mumps which is really rare, and it's even more rare for it to go in your ear and kill those hair cells and cause hearing loss. So I had complete hearing loss in my left ear. So, that has also caused a lot of issues.

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You know that everybody's been talking about food balance issues, equilibrium issues, I have really bad tinnitus.

Ali ([02:34:54](#)):

It's difficult being in loud environments and things. And I was sort of getting used to it with being able, getting better at reading lips and everything. And then COVID-19 hit. And I worked in a hospital as a physical therapist. So being in a loud environment, I couldn't function with mask. I couldn't read people's lips anymore. I couldn't hear with ventilators going, being in patients' rooms. I have to literally stand less than a foot away from somebody to hear them with my right ear, as close to them as I could possibly get. So I didn't realize it was affecting me as much, that much, but I would get home, I was exhausted all the time and I finally had to leave my work. Because I just couldn't function in there anymore. It's affected my relationships. I've had to try to be on people's left side so I can, they can hear when I'm walking, conversing with people I have to make sure I'm looking directly at them, no loud environments, especially during COVID-19, everybody's wearing a mask.

Ali ([02:36:02](#)):

I have noticed myself isolating even more and I was trying to wait for, I know there's some medical drugs that are on the horizon. So that has kept me from pursuing surgery, like the implant or anything like that. The hearing aid obviously doesn't work very well when you have a mask on, cause I have CROS hearing aids now and any kind of movement in my ear and the signal gets lost for my other ear. Or if there's any noise in the inbox, environmental noise, it's just really difficult. And I'm waiting for some medical drugs to come around the corner to ... and it's just been, it's been tough.

James Valentine, JD, MHS ([02:37:01](#)):

Sure. Ali, I really appreciate you sharing this and particularly the reality of the loneliness and isolation that you've just described. Could you maybe help us understand what are maybe things that before your hearing loss that you were able to do that now you're not able to do that are besides the work that are making it, you experience that loneliness.

Ali ([02:37:34](#)):

Yeah. Just being with friends, going out to dinner or going to a concert or going to a house party, pool party, you name it where there's lots of people around. And it's so difficult to try to have a conversation, even with my hearing aids on or even before I was functional. I was able to do anything I wanted and now it's just, I feel more isolated, struggling. Trying to figure out is it just COVID-19? Maybe when masks come off, I'll feel a little better.

James Valentine, JD, MHS ([02:38:10](#)):

Right.

Ali ([02:38:11](#)):

But yeah, I would say I was able to ... I can't do some of those things and I've noticed my memory's a little less, I have a hard time just trying to come up with the words that I want to say. And I don't know if it's because COVID-19, and you're already isolated or if it's because of the hearing loss that's causing this forgetfulness.

James Valentine, JD, MHS ([02:38:39](#)):

Thank you so much, Ali. I really, really appreciate you sharing this. It's important that we get this really full picture of the impacts of living with hearing loss. So thank you again I want to take a moment to broaden this one last time while we're still in this first topic discussion of understanding the impacts of living with hearing loss. And we've heard this already come up a few times, some worries for the future that we all have. And so we have a polling question. It's our final one of the morning. If you can go back, pull your phones back out or go to that tab, go to PolLEV.com/HLAA. We have a question for you about this topic.

James Valentine, JD, MHS ([02:39:28](#)):

So here we want to know what worries you the most about your, or your loved one's condition in the future? And again, we want you to select the top three greatest worries. The options are A: Not knowing if hearing loss will progress, B: Falling, C: Losing the ability to communicate D: Increased risk for dementia E: Not having energy to work or live as you want F: Not knowing if you can support yourself and your family financially G: Losing a relationship such as with a spouse or with a child H: Losing other social connections, or I: Some other thing that is your worry about your or your loved one's condition in the future that you would describe as amongst the top worries that you have.

Barbara Kelley ([02:40:22](#)):

James, there's a comment about "not knowing if I can support myself or family." Darja keyed in on this as did Ali, that the workplace is a problem. And we have a comment from Candice, from Eagan, Minnesota, who said, "I feel the most dramatic long-term impact is on perceived capabilities in the workplace. I find many employers have difficulty looking past an individual's perceived limitations instead of looking at the skills."

James Valentine, JD, MHS ([02:40:52](#)):

Wow.

James Valentine, JD, MHS ([02:40:57](#)):

So thank you for sharing that. And thank you for those of you participating in this polling question. We're seeing here again, just as a reminder, these aren't the percentages of people who have picked each option. It's the percentage of the total responses. So think of these bars as rankings. And what we're seeing is that the greatest worry about the future is the increased risk for dementia.

James Valentine, JD, MHS ([02:41:21](#)):

I think Ali even was alluding to some worry about that with his own memory. We also see H. Losing social connections as a top worry, followed by losing the ability to communicate, and then not having the energy to work or live as one once. Although we see each and every one of these worries selected as a top three worry by our participants today, as well as some others. And so we're going to want to hear from you here, now this morning. I guess we're now technically afternoon, but generally the morning session, as I was thinking about it, to talk about worries for the future. So I want to go to our phones first. I see that we have a caller. Suzanne from Massachusetts who wants to talk about some of the impacts during COVID related to her hearing loss. I think this is a theme we're hearing is kind of the learnings, both the good and the bad related to COVID. So Suzanne, welcome to the program.

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Suzanne ([02:42:36](#)):

Hi, and thank you so much for taking my call. So here's my deal, hearing wise I'm deaf in my left ear and have been since it was caught in a mass testing when I was six and I have Meniere's. Meniere's caused profound deafness in my right ear. So I'm pretty deaf, pretty darn deaf. So COVID has been awesome for me. And for two reasons, one is I work for a great company that's actually a data provider to the FDA. And I'm allowed to work from home and my ability ... so when I work in the office, my ability to hear depended a lot on which conference room I was sitting in and some conference rooms were fine and some conference rooms were acoustic, an acoustic nightmare.

Suzanne ([02:43:38](#)):

And when I'm working from home, our team sometimes uses WebEx and I can leverage the captions that annex and his team has. And actually my place of work also equipped me. I was given an accommodation of a dongle so that I can attach, hookup my hearing aid to my work laptop.

Suzanne ([02:44:14](#)):

So, I'm pretty much on a similar playing field as my colleagues, which is really, really nice. And it's funny, another thing that pandemic has impacted that may be might be a bummer for some people, but I don't want to go to a movie. I don't want to go to a concert. A friend of mine said to me once earlier, I think it was last year or something when Hamilton was a really big ticket on Broadway. She went there and she said, you know what? I loved it, it was wonderful. I couldn't, I just let the sound wash over me and I can listen to them, I can kind of follow the lyrics, but I just let the sound wash over me. And from my perspective, I thought, yuck, why would I want to do that?

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Suzanne ([02:45:03](#)):

Yuck! Why would I want to do that? So I, in fact, did watch Hamilton when it was made available on TV when it streamed for a little bit-

James Valentine, JD, MHS ([02:45:15](#)):

Yes.

Suzanne ([02:45:15](#)):

... because I set up my TV in my home environment, I've set it up so it can stream into my hearing aids. So I'm in this cocoon that is my house that is enabled by the job that I have. The stuff is not paid for by insurance. But I have this wonderful job, and I can sort of use aspects of that job to take care of myself with the hearing loss.

Suzanne ([02:45:46](#)):

Now I will tell you there is a bummer. There's a bummer for me at work, and that is it takes me about three to five times the effort to process people speaking during a meeting. And I use sometimes I use three layers of captions because captions, not everyone is perfect, but if I triangulate, I get a pretty good idea of what was said and what actions I need to take. But at the end of the day, I'm really tired, and I don't have a lot left to give. So again, some people consider this isolating, I call it I just want to log off.

James Valentine, JD, MHS ([02:46:31](#)):

Right.

Suzanne ([02:46:31](#)):

And I want to take my hearing aid out, and I just want to vegetate. So that's my story.

James Valentine, JD, MHS ([02:46:37](#)):

Yeah, and Suzanne, I think you painted a really, a great picture for us of kind of what it is to live with hearing loss for you, kind of how you've made accommodations within your own home and a lot of it due to the circumstances around COVID. So I really appreciate you helping us understand that.

James Valentine, JD, MHS ([02:47:02](#)):

I see that we have a lot of comments coming in also on the web. So do want to check in with Barbara on anything we're hearing, either impacts on activities in life or worries that people have expressed.

Barbara Kelley ([02:47:17](#)):

Yes. We have a lot of people coming in talking about being in the workplace, and Darja talked about this. Ali talked about it. And I had a comment here. It's escaped me, but a woman said that "she retired at age 58," James, and it was really a complete abrupt to her really successful nursing career. And she felt that she "could have gone on had it not been for her hearing loss."

James Valentine, JD, MHS ([02:47:43](#)):

Sure. And I also want to check in with our panel here. I think we have Tony and then Darja to help weigh in on this question of worries for the future. Tony, could you get us started? When you think about this, what are the things that worry you the most about the future living with hearing loss?

Tony ([02:48:05](#)):

Well, what worries me the most is the dementia, the link between the hearing loss and dementia. I'm really hoping for a cure. As I've mentioned earlier, my hearing loss is hereditary, and I see it with my dad. He's already got dementia. I'll probably be there too.

Tony ([02:48:27](#)):

His hearing, he grew up in a little bit different era. Fortunately, I didn't need a hearing aid until I was 20, but I needed one earlier, but I didn't get one. There was a social stigma for that, but really the dementia is I'm seeing it now. He wants to die. And I just hope that I don't get to that point.

James Valentine, JD, MHS ([02:48:53](#)):

Sure. Thank you, Tony. And Darja?

Darja ([02:48:59](#)):

Yes. I'm not afraid of dementia, but I'm afraid that when I will be old, nobody will help me with using my cochlear implants because maybe young people don't know enough about that, how to put on the right place on both side, and that if the cochlear implants move, then you are not able to hear. And I'm really

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afraid that maybe I will not be able to put my cochlear implant on my head. And because I worked with the health workers, I've tested them, young people. I tested them on me, if they're able to put hearing aids, my old hearing aids on my ear, and they were not able to do it. They hang up a hearing aid in some way like a Christmas decoration on my ear. It was the same.

Darja ([02:50:06](#)):

And also I'm afraid how to keep up with the technology, the technology is exploding now. And it is so hard to follow everything, to connect everything together, to switch from one app to another app and then another app, and that is not so easy. I'm not so old, but I have problems with that. So, I'm afraid how to educate young people to help older people in all devices. And I think that this is our mission too.

James Valentine, JD, MHS ([02:50:49](#)):

Yeah. A very, very practical worry there, Darja. So thank you. I think we have time for one final caller. We have Eloise from Florida who wants to share some of her experiences with hearing loss. I'd like to welcome you to the show.

Eloise ([02:51:06](#)):

Yes. Hi.

James Valentine, JD, MHS ([02:51:08](#)):

Welcome.

Eloise ([02:51:08](#)):

Hi. I'm Eloise [Short 02:51:10], and I am a retired disabled nurse. And I know previous caller had talked about her experience. With mine, I was born with hearing loss, probably genetic. I've not had it checked out. However, my career as a nurse of 40 years was interrupted by the hearing loss.

Eloise ([02:51:36](#)):

My hearing loss wasn't discovered until I was 50 years old. And although my parents knew I was hard of hearing, they tried to cover it up. And I always knew there was something wrong with me, but I didn't know what it was. And I worked very hard to figure out what was wrong with me, but I worked as hard as I could to figure out what was wrong with me.

Eloise ([02:52:03](#)):

And I had a lot of problems. I had three car accidents when I was younger. I was in a coma. I had lots of different problems because of that. I had surgeries. It was discovered I had two aneurysms in my brain. I had viral meningitis. I had a surgery that led to sepsis. I had antibiotics to save me. I had all the different kinds of encounters that caused me to have difficulties with my hearing loss, including tinnitus, hyperacusis, and everything that controls things with my balance and my hearing loss.

Eloise ([02:52:46](#)):

But then it was discovered because I was falling all the time and had the neuro testing done that I had organic brain syndrome. It was discovered in the year 2004. So I've been battling the memory loss for since that time. I am registered with the Alzheimer's Association, and I have two other organizations

that are following me and tracking me. I've been part of a lot of their different programs nationwide. And they're following me because of the fact that there is a slow loss of my memory. And of course, I have a mushy brain. I mean, my MRIs are followed every two to three years. I have five different neurologists that are tracking me. I have migraines that are multi-focused, and I micromanage myself because I am a nurse. I'm aware of that.

Eloise ([02:53:56](#)):

But my hope is that, and what I do as a HLE advocate and educator is that I hope that the future prevents this from happening. We don't need to be waiting at 50 years of age for people to discover that they're hard of hearing. We need to be advocates from the point of birth and forward, not wait until you're older.

Eloise ([02:54:29](#)):

And then covering for hearing aids, all of my hearing aids were not high end. The one that I have now is the highest that I can pay for, but I have been an advocate for the last 10 years to get Medicare to cover for hearing aids-

James Valentine, JD, MHS ([02:54:46](#)):

Thank you, Eloise. Thank you.

Eloise ([02:54:46](#)):

... but also for insurance coverage to be covering for them because I this is the last hearing aid that I can afford because I don't have any money to pay for them. So in the many things that I'm doing to advocate in this 55 community that I live in.

James Valentine, JD, MHS ([02:55:09](#)):

Yeah, thank you so much, Eloise. And again, I think so important to hear about the need for testing and really for Eloise telling us about how your hearing loss was not found right away. And you had so many issues associated with that.

James Valentine, JD, MHS ([02:55:33](#)):

I do realize that we're a few minutes over schedule here, and I want to make sure we have enough time for a little bit of a lunch break, but I really want to thank all of you. And I want to thank our Zoom panelists that we have here on the screen, all of you that have called in and written in on this first topic of what it is to live with hearing loss.

James Valentine, JD, MHS ([02:55:54](#)):

When we come back after the break, we're going to build on this discussion and really dive a little deeper into your experience with different approaches to treatment and explore how those have worked for you and what your treatment goals are for the future. So tune back in at 12:55, that's Eastern time. We'll come back from break then and dive into this topic. Thanks again. And we'll see you momentarily.

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James Valentine, JD, MHS ([02:56:18](#)):

(silence)

PART 6 OF 10 ENDS [03:18:04]

James Valentine, JD, MHS ([03:21:36](#)):

Hello and welcome back to the Externally-Led Patient-Focused Drug Development Meeting on Sensorineural Hearing Loss. I'm James Valentine, your meeting moderator here with Barbara Kelley from the Hearing Loss Association of America, my co-host for today. As I mentioned, as we were coming on to break, we have the opportunity now to hear from individuals living with hearing loss and their direct caregivers to expand upon our understanding of living with hearing loss by now exploring topics related to approaches to treatment. I'd like to pull up our discussion questions that we're going to be asking you to weigh in on here over the next audience discussion session that we have together. So we're going to start off focusing on currently available treatments. We want to understand what you are doing to help manage you or your loved ones hearing loss symptoms. When we talk about what you're doing to manage, or when we generally refer to treatments here, we're really casting a wide net.

James Valentine, JD, MHS ([03:22:43](#)):

We want to know about any medicines or medications, any medical procedures, medical devices that you use, but also other things outside of kind of traditional medical treatment, whether that's lifestyle modifications that you make, strategies for communication, really anything that you might do to make living with hearing loss just a little bit easier. We are going to explore how well these different treatment approaches help with your most significant symptoms of hearing loss. As well as, explore the downsides that come with those treatment approaches whether that's side effects, the burden of actually using the product or having the treatment, anything that you might view as a downside associated with your treatment.

James Valentine, JD, MHS ([03:23:32](#)):

And then once we've explored the currently available treatments, we're going to end the session exploring that short of a complete cure for your hearing loss. What specific things would you look for in an ideal treatment for hearing loss? Another way to think about this is, if you were considering a new treatment for your hearing loss, what factors would be important to you? So begin thinking about these questions, but to help in getting this discussion started, we have another panel of members of your community. We have Zina, Brenda, Mike, Veronica, and James who are going to be sharing their treatment stories. So Zina take it away.

Zina ([03:24:16](#)):

Imagine not being able to distinguish between the sounds L and R, M and N, G and D. How can you tell the difference between lore and rule, Mansi and Nancy, go and dough? What if those words spoken quickly in complex sentences. This has been my experience growing up with hearing loss. My name is Zina Jawadi. I have a bachelor's and master's degree from Stanford University, serve on the board of directors at the Hearing Loss Association of America, and I'm a first-year medical student at UCLA. I was diagnosed with hearing loss when I was 3 1/2 years old. At such age, most children acquire language naturally, and can recognize 1,000 words, but I only knew a few. That is not surprising. After all, how can a child learn how to speak without hearing the words. I was fitted with hearing aids and over the next

eight years, I had to work thousands of hours to, in and from speech therapy. My therapist would mold my tongue saying it is not R it is R, curl your tongue.

Zina (03:25:25):

We would play Go Fish together so that we could practice saying words like three. My auditory verbal therapist spoke behind me to rely on my residual hearing in order to discern what was being said. I was frustrated to spend so much time in therapy instead of playing and to be honestly pushed to correct my pronunciation, which I repeatedly failed. Yet, this experience equipped me with persistence, a strong work ethic and holistic listening. It is ultimately because of speech therapy that I can speak and follow conversations without extensive reliance on lipreading. In almost every educational setting, I have been an underrepresented minority and almost always the first person with hearing loss that my colleagues and instructors have ever encountered. I have faced onerous obstacles. From the lack of microphone use in most large lecture halls to refusals by many professors to enact accommodations for my hearing loss.

Zina (03:26:24):

In addition to wearing my hearing aids, I've used captioning, sit in the front row, create visual diagrams and attend office hours. Finding a captioner who can transcribe the highly technical material was challenging, but I'm extremely grateful to have had the same exceptional captioner in undergrad, masters, and now medical school. COVID-19 significantly increased my listening fatigue. With face masks I cannot supplement my hearing with lipreading. To compensate the listening fatigue that I, and most people with hearing loss face, I take naps after class and go for walks. I spent significantly more time studying than my classmates since universities rarely teach accessibly, for people with hearing loss. In medical school, learning anatomy was exhausting with noisy labs, masks, social distancing, and face shields. My new hearing aids and Bluetooth microphone are excellent for one-on-one conversations in quiet environments, but fail me in the lab where we work in groups.

Zina (03:27:28):

It was especially difficult because I was not yet familiar with the terminology to contextualize conversations and fill in the gaps of what I could not hear. I spent countless hours in the lab. Eventually I obtained permission to work alone because there was no way for me to maintain social distancing and hear my partners. This change was highly beneficial, as it took me a fraction of the time to learn anatomy henceforth.

Zina (03:27:54):

My classmates had a wide range of stethoscopes to select from, with a variety of colors, personalizations, and price points. In contrast, it took me months to find a workable stethoscope. I spent hours doing research online, contacting manufacturers and purchasing different stethoscopes to try. Once I selected a stethoscope, I have to ask an instructor to try my stethoscope and teach me how to use it because it has different features than standard analog stethoscopes.

Zina (03:28:24):

I became teary when I've heard the heartbeat with the stethoscope for the first time. It was one of the most beautiful sounds I have heard. The ideal hearing loss solution would enable me to effortlessly communicate in group settings, even with poor acoustics and loud background noise. I defined effortless

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communication as the ability to actively engage in conversations without leaning forward, experiencing listening fatigue and asking people to repeat. Such solution, would for example, provide accurate speech recognition in quiet and noisy environments and to produce clear loud sound. The solution should be user-friendly, easy to learn and to acquire less than 15 seconds to turn on. Finally, solutions for prelingual hearing loss should enable children to hear in classrooms and facilitate language learning. Most importantly, all technologies should be affordable and covered by health insurance. Hearing health care should be a right, not a privilege. Thank you.

Brenda ([03:29:36](#)):

Good afternoon. I'm Brenda Battat. I inherited hearing loss from my father. I was diagnosed at 19 with a moderate sensorineural hearing loss. My hearing loss has progressed to profound in both ears. And I now use a cochlear implant and a hearing aid. Treatment for my situation has been learning how to manage and live with the impact that hearing loss has on my ability to function every day and to maintain my quality of life because there is no cure. This has meant using hearing aids. First one analog then two digital. An FM system, a telecoil to use with phone and loop systems and a powerful volume control for the phone. Sudden tinnitus was treated with bilateral hearing aids to mask the tinnitus but when removed at night, it is difficult to sleep.

Brenda ([03:30:27](#)):

My audiogram plateaued, but my speech recognition plummeted. And then I was forced to communicate visually, caption telephones and entertainment, flashing alerts. Hearing aids by now only work for me in quiet environments with no more than two people who enunciated clearly, without accents and no reverberation in the room. The result was a severely reduced quality of life, leading to self-isolation, sadness, feeling alone and locked out of life in spite of a very supportive husband and family. At this point, my speech recognition was 4% and I sought a cochlear implant. The surgery was outpatient under general anesthesia, lasting about two hours. An internal component is placed in the cochlear that connects via magnet to an external processor worn behind the ear. A side effect for me was a loss of taste that lasted several months. The incision behind my ear healed and then I was activated. The sound was tinny, men's voices sounded like women's, but within two months, my brain identified sounds it hadn't heard for years.

Brenda ([03:31:36](#)):

The processor was programmed daily, post-surgery, then weekly, then less frequently. Now I go once a year for tune-up and in-between change the microphone covers to keep the sound crisp. I replace two, 675 batteries every other day. Over time, the implant returned me to the world around me. Birds, neighborhood dogs, microwave beeps, some music and movies. My speech comprehension increased from 4% to 80%. Driving was less daunting as with a cellphone I could handle an emergency, hear passengers in the back and the radio. I'm now 18 years post implantation and have upgraded the external processor four times to benefit from advances in technology. I now have a one piece device, nothing behind the ear anymore that connects directly via Bluetooth to my iPhone. I look forward to a completely implanted device.

Brenda ([03:32:32](#)):

In spite of the technology, I cannot hear everyone on the phone. I may ask the caller to text me or use captioning apps if necessary. I still need captioning for TV, streaming and Zoom calls. I still don't relish

social gatherings because the background noise makes it hard for me to have a conversation. I still rely on speechreading.

Brenda ([03:32:53](#)):

Two years ago, an event occurred that focused my attention on the genetic aspect of our family hearing loss. Over a two month period, three members of my family were diagnosed with hearing loss. We knew that my son had inherited the gene, but now my adult daughter and two ten-year-old grandchildren were affected. Suddenly we had seven hearing aids and a cochlear implant between us. Within two months, they identified the gene DFNA5, hearing loss that appears early in life, but not at birth. The biggest shock was that all five grandchildren had the gene. I found that for over decades, scientists have been working to develop gene therapies for hearing loss. This is not surprising given that 80% of hearing loss has a genetic origin. There are several approaches to genetic and regenerative therapy being studied in animal and human models to restore the ability to understand speech and not rely on devices that amplify some, but do little to age intelligibility. I've signed up to be part of a research project, looking for treatments in humans. I'm not expecting results for myself. I'm aiming for my grandchildren.

Brenda ([03:34:08](#)):

I believe these approaches are the future. Getting at the root cause of the hearing loss. This would impact our family tremendously. A great outcome, especially for my grandchildren, would be to stop the progression of the hearing loss, nip it in the bud. Eventually I hope we can erase the mutation, stamp it out entirely from our family, so it cannot be passed to the next generation. In the meantime, we have devices. The holy grail of hearing device innovation is eliminating background noise and enabling intelligibility. Until this is achieved devices will fall short and as long as the miniaturization is a goal, it's unlikely to happen.

Mike ([03:34:52](#)):

Hello, my name is Mike Miles. I am 63 years old and have bilateral, moderately severe sensorineural hearing loss resulting from otosclerosis in my early 40s. Otosclerosis is a bony overgrowth in the middle ear that prevents the ear from hearing properly and also affects the inner ear. One of the common results from this disease is that the stapes bone collapses and blocks the passage to the inner ear, leaving a person deaf in that ear. A surgery called a stapedectomy is performed, which removes the damaged bone and attaches a titanium replacement. I've had that surgery in both ears. And the next day after the packing was taken out, I could hear again with moderate hearing loss, instead of being deaf. It was like having a switch flip from off to on in my brain.

Mike ([03:35:43](#)):

I started wearing in-the canal hearing aids because I didn't want to wear visible hearing aids outside of my ear. But as my hearing loss got progressively worse, I realized I had to swallow my pride and purchased a pair of behind-the-ear aids. The other benefit with these aids is that they came with a telecoil and that's helped very much when I'm in a large room with a hearing loop like church or an auditorium.

Mike ([03:36:09](#)):

I've been experimenting with different assistive listening devices, not very successfully, such as microphones or streamers because the hearing aids themselves have limitations when it comes to

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listening and noise. I have just as much difficulty hearing in a restaurant as I do when I'm outside playing golf or playing tennis. My first success with assistive technology was when I purchased made for iPhone hearing aids. I'd been avoiding answering my cellphone for many, many years because of the difficulty hearing people on the cellphone and the hearing aid. And also the feedback I would get from the hearing aid, whenever the phone pressed up against the ear, it was very aggravating.

Mike ([03:36:53](#)):

Now I have the phone ring right in my hearing aid using Bluetooth. I tapped the hearing aid and the person's voice goes directly to my ear, without the phone being held. I also have it attached to my iWatch so the watch vibrates when the phone rings. This has been a tremendous improvement for me with the phone as now I have clear phone conversations as well as allow me to listen to music on my phone when walking and videos on the laptop. However, Bluetooth does have some limitations when walking outside the connection periodically disconnects while listening to music. And my current hearing aids only allow one Bluetooth connection at a time. So I can't have my laptop connected and also answer the phone in my hearing aids at the same time. My hearing wishlist would include for the next five years, something either technology-related or biologics that would help offset the damage done to my inner ear so that I could hear better in noisy situations.

Mike ([03:37:56](#)):

I'm not sure normal hearing people really understand the stress and anxiety that we experience in social settings. The pandemic social distancing and the mask wearing has made it significantly worse. It would be great to go out to dinner or social settings and be able to hear what the other person or people were saying at the table, or to hear my wife and daughter in the car when we're driving. Right now that doesn't occur. I'm not looking for a complete reversal of the damage, but any improvement would make a big difference in mine and my family's lives.

Mike ([03:38:34](#)):

I also would like to see manufacturers make continued improvements to make the hearing aids smarter through recognition of certain voices in crowds. And the ability to block out extraneous sounds such TVs or music in restaurants.

Mike ([03:38:50](#)):

Captioning is very important for people with hearing aids. I'm using captions on my cellphone, when the person I am talking to is difficult to understand or has an accent. I also am using them on video meetings and webinars, and I'm very thankful to the video companies that have made captioning available on their platforms during the pandemic. I would also like to see more attention and solutions to address the emotional challenges that we face. When I was teaching high school, I would come home at night and collapse from the stress and anxiety because of my brain having to work overtime all day, trying to figure out what the students were saying. I tried working with a therapist, but it didn't help. I eventually had to stop teaching. I'm keeping a positive attitude as I look forward to improvements for those of us, with hearing loss in the near future. Thank you.

Veronica ([03:39:45](#)):

My name is Veronica Davila-Steele. I am a resident of Prince George's County, Maryland. After a visit to the emergency room, when I was 48 years old, I was diagnosed with vertigo and sent home with

medication for motion sickness. I later realized that I had lost hearing in my left ear and contacted my doctor who referred me to a specialist at Georgetown University Hospital. The specialist had me come in the next day because, in some cases, the inner ear steroid injections within 48 to 72 hours can restore your hearing. I was treated with weekly injections, as well as oral steroids for six weeks. Although with my initial visit and injection, I had very minimum hearing in my left ear. I subsequently lost all hearing within a five-day span. Unfortunately, after the six weeks there was no improvement, which was one of the things that doctors warn was the possibility.

Veronica ([03:40:47](#)):

Approximately 15 months later, I had a second vertigo attack, which caused significant hearing in my right ear. Since I have prior experience and treatment protocols, I reached out to my ear nose and throat doctor, and start at the steroid injections and oral medications, after my audiogram indicated 60% of hearing loss. I also started a 10-week series of hyperbaric chamber treatments at George Washington University Hospital. They were one-hour sessions, five days a week in an enclosed chamber with saturated oxygen. None of the rich treatments restored my hearing. So, I got my first hearing aid at the age of 50.

Veronica ([03:41:32](#)):

The hearing aid worked very well until my hearing took another dive. The hearing loss was so profound that I had to get a cochlear implant in my left ear. Five years to the date of my vertigo attack and hearing loss, I was elected to get a bilateral cochlear implant. Over time these devices continue to evolve with new technologies that allow for ease of use in daily activities. My first cochlear implant did not allow me to stream directly into my device. My second, newer model allows me to have direct connection to cellphones, to the television and any place that has a hearing loop. And it also helps with directional sounds.

Veronica ([03:42:19](#)):

I also benefit from the use of closed captioning, which helps me to fill in the gaps that I may otherwise miss in communication. My treatment routines have included scientific, technological, holistic approaches and dietary changes. Each serves a specific purpose. At one point I had daily acupuncture treatments with over 200 needles placed throughout my body. Eliminating inflammatory foods from my diet helped to alleviate sinus issues and ringing in the ears, also known as tinnitus. The hearing aids and cochlear implants help to provide with a mechanism to hear again, but I believe the acupuncture treatments help the most. And by alleviating the lingering effects of vertigo, such as loss of balance and fatigue from brain fog, and which is an ability to stay focused and for clarity. There are times that I get frustrated that I cannot hear every word in the conversations. This is one downside of the devices because they have limited range and distance, as a normal hearing person would have.

Veronica ([03:43:35](#)):

Short of a cure, I would like to see advances in the directional sounds and distances. Currently, both devices, cochlear and hearing aids have a six foot hearing range. This means I often have trouble hearing if someone is in another room or across the room.

Veronica ([03:43:55](#)):

I also cannot distinguish where my phone is or have a sense of direction if the phone rings and it is too far away. I have to constantly place it in the same place so that I can quickly find it when it rings. The elimination of background noises and social settings, and the capability to distinguish sounds such as sirens and musical instruments would be a big plus. Ultimately, in addition to these technological advances, I would like to see more research on stem cell treatments to someday come up with a cure.

James B. ([03:44:35](#)):

My name is James Battat. I'm a husband and father of three children. I am Brenda Battat's son. Anna [Westrick], who you heard from the first panel, is my sister. I am a physics professor at Wellesley College near Boston. I inherited my hearing loss from my mother, just as she inherited it from her father. As my mom described genetic testing recently showed that I passed my hearing loss on to all three of my children. They are 12, 11 and six years old. When Anna and I were kids, we knew nothing of the DFNA5 gene, but we did know that we were at risk of inheriting hearing loss. So we were tested regularly. I dreaded those visits. When I turned eight, my audiogram showed loss at high frequencies and it got worse each year. The unrelenting march of a progressive hearing loss.

James B. ([03:45:23](#)):

Hearing aids would have benefited me as early as high school and certainly in college, but I couldn't bring myself to take the plunge. I was doing fine, I thought. Hearing aids were for elder adults. I'd get one eventually, but not yet. But like many with hearing loss, I was a terrible judge of what I was missing.

James B. ([03:45:41](#)):

So I've been wearing two hearing aids now for nearly 20 years. I've tried several different brands and worked with many audiologists. Your choice of audiologists, I learned, restricts your choice of hearing aids because most audiologists only carry a few brands. That used to bother me, but now it seems hardly to matter in practice. Essentially, the only reason that I wear hearing aids is to understand what people say, what my wife says, what my kids say, what my students and colleagues at work say. But when I asked my audiologist, which hearing aid will help me hear speech and noise, she says, it's hard to say let's try some and find out. So here's what that process looks like.

James B. ([03:46:20](#)):

I go to an audiologist office. She gives me a demo hearing aid and based on a few minutes of trying it out in the office, I choose one that sounds good to me. A few weeks later, I returned to pick up the new hearing aids. Because they can't be reprogrammed remotely, I must return to her office for every adjustment. Some for the better and some not. At some point, I just give up and say, it's fine like this. Not because it actually is fine, but because it becomes too hard to justify taking time off of work again for another adjustment and marginal improvement.

James B. ([03:46:52](#)):

But I wear these imperfect devices every waking moment. They work well as streaming devices. At work meetings I can couple them to a loop or a remote microphone. My phone will stream calls and podcasts to my ears by Bluetooth. I take Zoom calls on the computer in the same way. But I struggled to understand regular speech. I can't hear my wife when she talks to me from another room. When I watch

TV, I rely on close captioning. When I'm driving I can't understand what my kids say if they're sitting behind me. I know it's not safe, but I turn around to see them in hopes of hearing them better. On my bike, I rarely hear cars approaching from behind. In the classroom, more often than not, I must ask my students to repeat their questions. That gives me a little time to walk closer to them and have a better chance of hearing.

James B. (03:47:39):

Social interactions are exhausting for me. As my hearing degrades the cost benefit of those interactions shift and I find myself opting out more and more, although it doesn't really feel like a choice. COVID-19 provided a terrible relief for me. No more large gatherings, no need to balance my desire to interact with the stress and frustration of not being able to participate fully in the conversation. Teaching on Zoom means I have much easier time of hearing my students.

James B. (03:48:06):

I know that my hearing will continue to degrade, which is hard to stomach because even now I know that I'm not living my best life. I can cope with this for myself, but I can't accept the same situation for my sons and daughter. My two sons, kindergarten and sixth grade, already show signs of loss. The other day my six-year-old said, very matter of factly, that he thinks he needs a hearing aid. I found it very hard to hold it together, as I talked to him about it. On the one hand, it's a relief that he has the vocabulary and the openness to express it, but it's also devastating. He really has no idea of the challenges that lie ahead. My family needs better hearing solutions so that we can live our best lives. In the very short term, telehealth options for hearing aid adjustments would provide some logistical benefits, but even then hearing aids do not help me hear speech and noise.

James B. (03:48:54):

We need better devices to improve speech intelligibility. Looking ahead, we need medical treatments to limit the extent of genetic hearing loss, so my children's loss does not progress as far as my own has. I want them to participate fully in their social and professional lives in ways that my mother and I have not been able to. Most of all, we need medical treatments that, as my mother said, get at the root cause of genetic hearing loss by suppressing the effects of genes, like DFNA5 or preventing them from being passed on in the first place. That way my grandchildren won't even need to think about hearing or hearing loss. Thank you very much for listening today.

James Valentine, JD, MHS (03:49:41):

Thank you, James, and all of our Panel 2 panelists for really walking us through, not only your personal experiences with hearing loss, but really digging into the topic of treatment approaches and really evaluating them for us, what has worked well, what hasn't, or were there still needs that you have, and also sharing some of the downsides and what you're looking for in the future. These are exactly the topics that we're going to explore here together as part of this next discussion. If you have thoughts, input, would like to share any of your experiences with treatment approaches, I want to, at this time, remind you that and invite you to dial in. That phone number, as a reminder, is 1.703.844.3231. Again, that's 1.703.844.3231.

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James Valentine, JD, MHS ([03:50:36](#)):

We really enjoyed hearing from so many of you this morning in our earlier session. We would love to continue to hear from you on these important topics that are going to help round out our discussion. But like in the earlier session, we want to get started with some polling questions to get us thinking about these issues. And so please go ahead and pull your phone back out, pull up that browser, open that tab on your computer.

PART 7 OF 10 ENDS [03:51:04]

James Valentine, JD, MHS ([03:51:02](#)):

Go to that browser or open that tab on your computer and go to [PolLEV.com\HLAA](#). You can keep that open and work through all of the questions that we have for the remainder of the day. If you're just joining us. This is for our individuals living with hearing loss and their direct caregivers. To please answer these questions. And this first one we're going to ask you about is to get a sense of our audience, what medications, medical treatments or technology solutions you have used to help with your hearing loss. And here we want you to select all that apply. The options are A: a single hearing aid, B: bilateral hearing aids, C: cochlear implants, D: bone anchored implants, E: steroids, F: speech therapy, G: counseling or behavioral therapy. H: an anti-depressant or an anti-anxiety medications. I: other medications, or J: if you have not used any recently. We'll be expanding in our next question on other types of treatments. So here we're really focused on medications, medical treatments and technology solutions.

James Valentine, JD, MHS ([03:52:18](#)):

As a reminder for the polling results, we're seeing percentages of responses. And since individuals could select all that apply, we're seeing the percentage of total responses. So think of these bars as a ranking, and as it stands, we're seeing the most common treatment experience of those we have represented today being with bilateral hearing aids. After that so far, it looks like we're seeing single hearing aids and cochlear implants is kind of the next two. Followed very closely we're seeing some jumps here in counseling and behavioral therapy and antidepressants or anti-anxiety medications. But we are seeing some representation with use of each of these different types of medications and technology is with only a small proportion reporting that they have not used any of these approaches.

Barbara Kelley ([03:53:17](#)):

And James that really tracks with the national data we have on hearing aid use and cochlear implant use. We know that 5% of people who could benefit from a cochlear implant have one and the majority are hearing aid users.

James Valentine, JD, MHS ([03:53:35](#)):

Great. Well, I want to thank everyone for answering this. We're going to expand this and go to our second question. And in this second polling question, you'll see, we want to know that besides those medications and treatments, what else are you currently doing to help manage the symptoms of hearing loss? And again, we want you to select all that apply a lot here. This includes A: increased exercise, B: modifications or accommodations in the home. C: healthy diet, D: assisted listening systems, E: captioned telephone. F: captioning on TV or internet, G: apps for listening or speech to text. H: alerting devices. I: stress management, J: acupuncture, K: dietary supplements, L: increased non-verbal communication, M: some other way that you're helping manage your symptoms of hearing loss

that is not represented on this slide. Or N. if you're not doing anything to help manage your symptoms. And again, please select all that apply.

Barbara Kelley ([03:54:53](#)):

It's really great to see, James, that we have... Looks like a lot of people who are using hearing assistive technology. That would be something in addition to their hearing aids that they might end use with their hearing aids or cochlear implants, like using a hearing loop or something else and, of course, we see captioning and caption telephone use.

James Valentine, JD, MHS ([03:55:18](#)):

Yes. So we're seeing quite a lot of strategies used. As was just mentioned, captioning and assistive listening, being perhaps the top, followed closely with apps for listening or speech-to-text, as well as modifications and accommodations in the home. But we are seeing quite a few of these stands out as increased non-verbal communication. We started to hear about some of those strategies earlier today with of course, want to hear more about that. We don't see many people using dietary supplements or acupuncture, although they are used. And we do see some other strategies being used that aren't listed here, want to encourage you to call in or write in using that comment feature under the live stream to share those experiences. And then there are some that are not currently doing anything to help manage symptoms. All right. One more polling question, before we jump into the discussion.

James Valentine, JD, MHS ([03:56:17](#)):

So this question is we want to know thinking about all of those things, both the medical and nonmedical, how well does your current treatment regimen control your overall condition? So all of those things you helped us understand in terms of the symptoms and health effects of hearing loss. How well does your current regimen control or help with those different symptoms? The options are A: not at all, B: very little, C: somewhat, D: to a great extent or E: this question is not applicable because you are not using any of those. You do not have a current treatment regimen. You're not using anything. So we'll ask you to think about this, characterize it and really use this as a tool for helping think about how much do the tools that you have currently help you. What does that help look like?

James Valentine, JD, MHS ([03:57:15](#)):

Have you noticed that it helps? But also how do you notice what else you still need in terms of treatment gaps or treatment priorities that you have. And that's exactly what we want to hear about. As it stands, it looks like a little over 60% say that their current regimen helps them somewhat. Just under 25%, say it helps to a great extent while 8% reports that it helps very little and no one reporting that it doesn't help at all. And then again, we still have consistent with the previous polling questions, a small number of people who are currently not using anything. And even during this discussion, which is focused on treatments, we do want to hear that perspective, the person who's not currently using anything. Why is that? Is it based off of where you are in your kind of hearing loss journey?

James Valentine, JD, MHS ([03:58:07](#)):

What were your deciding factors to help you arrive at applying no treatment approaches individually? So looking forward to hearing about that, but now I want to take us and introduce you all to our Zoom panel. Like before we have some courageous individuals who have agreed to participate in the discussion with us today. Before I go to them, just we'll remind you this is a great time to call in, dial in at

1.703.844.3231. And then also of course reminds you that you can write in use that comment feature under your livestream. As we move through this discussion if you hear something that resonates with you, you have something to share at any time, please call in or write in. We would love to get your feedback. So thinking about current treatment regimens and how well it's working, I'd like to perhaps focus on those things that have been helpful. And I think we saw from that latest polling question, that for most people, they are getting either some or to a great extent help from existing treatments. And so perhaps Lise, you could start us out when you answered that question what were you thinking? And can you share an example or two of treatment successes. Lise, I think you're still on mute.

Lise H. (03:59:39):

Problem, always muted, right? I'm Lise Hamlin. I've had a hearing loss since birth on my left side. And on my right side, I have about almost 40 years ago I had a sudden hearing loss literally overnight. And so now I'm a severe to profound hearing loss. And when I thought of that polling from a question and the problems we have and how do we treat it, what I've done is I have a cochlear implant on one ear, and I have a hearing aid on the other ear, but like James Battat was saying different situations need different things. We use all kinds of tools to help us go from day to day from captioning to assisted listening devices, to speech reading, to alerting devices. We use every tool in the book so that we can communicate with other people.

James Valentine, JD, MHS (04:00:32):

And what have you found to be, you know maybe it's not the thing that helps the most, but maybe a treatment success that you think is noteworthy to share kind of a specific example.

Lise H. (04:00:45):

I think I couldn't live without my... I guess I could live, but I couldn't work and communicate without my hearing aid and my cochlear implant. So that's really the most important tool I have. There are fabulous and I really love them, but they can't do everything. So will use the assistant listening devices using a loop and a meeting room. That's really a hearing loop and a meeting room is really a big help. So my cochlear implant needs assistance just like I do. My hearing aids do. And so I'll use what's appropriate to the situation. Sometimes I'll use a speech-to-text app too. Sometimes that's very helpful. And today we have captioning, which is really, I'm highly dependent on that as well.

James Valentine, JD, MHS (04:01:29):

Sure. And maybe for those of us that aren't as familiar with the hearing loop, can you kind of describe what that is and when that's useful?

Lise H. (04:01:39):

Okay. The hearing loop is an assistive listening device it's used in meeting rooms or large areas, or actually you can have it in small areas too. It's literally, or it used to be literally a wire that goes around the room, or it could be around your chair. And then it's linked to a microphone where somebody speaks into, and then it sends a signal to your hearing aid and now cochlear implants too, as long as you have a telecoil in those devices. So that will allow somebody to use in system, you walk into a meeting room, just switch over to your telecoil and you can hear in that situation. They're are huge help and as I say, some people use them in their living room to hear the TV, if they're not using Bluetooth or some other way to connect with those.

James Valentine, JD, MHS (04:02:26):

Absolutely. Thank you so much, Lise. I want to turn to Russ on this. Thinking about this same topic of what have you noticed to be most helpful? We'd love to hear your thoughts.

Russ M. (04:02:40):

Thank you. My name is Russ. I've had a hearing loss for about 25 years or so. The technology is questionable. As a child, I had severe ear infections and they were treated, and this sounds weird to today's treatment regimens, but they treated it with massive doses of x-ray. That made me sick and did not solve the problems so they went to plan B, which was radium. That barely probably solved the problem. And for 40 or 50 years after my hearing was pretty good. There is some speculation that might've been the origin of that kind of treatment, might've been the origin of the hearing loss which occurred later, but [inaudible 04:03:37]. My hearing loss and sensorineural, it's started out moderately about twenty-five years ago and it's progressed. It is now severe in my left ear where I use a hearing aid and became profound in my right ear.

Russ M. (04:03:58):

And for the last eight years or so, I've had a cochlear implant. In terms of what I use. Well, obviously of course I use the assistive devices. I use variety of hearing assistive devices as well. I do, you know following on Lise, I have looped a television set, which actually works very, very well. It works well in a couple of ways I can hear quite well and at the same time I can mute the output and my wife or whoever else is there can turn it up to whatever volume they find comfortable with. And occasionally they'll walk into the room and say, "I can't hear anything." Because I'm obviously hearing quite well]. Speech-to-text apps as well. And I use, which I use Bluetooth, small Bluetooth microphone, which I find very, very useful. Still on all when asked the question on the polling, I answered that what I'm using it addresses the problem somewhat, but there's still a lot going on that still needs to be addressed.

James Valentine, JD, MHS (04:05:30):

Thank you so much Russ. Appreciate you sharing those different strategies and kind of giving us a glimpse into even how that helps with the family around the house. Want to throw it over to Don real quick because I know Don you have a treatment approach that you'd like to speak to.

Don D. (04:05:51):

Yes, thank you. My name is Don Doherty and I live in beautiful downtown North Carolina, and I'd like to speak to something that I went through. I lost my hearing in Vietnam. I was in denial for a little bit, tried to make do. But I was medically evacuated about two years later from Puerto Rico, mainly because I couldn't understand whispers at night. I ended up at Philadelphia Navy hospital, which wasn't there. And I learned that the military actually had, in addition to your testing and evaluation, they had all of the rehabilitation courses. And over the years they stopped that. But back in 1970, when I went through, it was a very opportune moment for me because they went into speechreading. They went into how to position yourself, join difficult speaking environments, going outside with your hearing aid, to manage background noise, showing the difference between different situations.

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Don D. ([04:06:56](#)):

And I really got out of that, got a lot out of it. And so after everything was done, I appealed the recommendation to discharge and I was able to stay in the Marine Corps, but that knowledge was certainly helpful in dealing with it. So for me, well, rehabilitation is not provided by the VA right now or by no nearby audiologist. And so we had to seek out groups like HLAA or other support people truly educate you. And I'll talk later about some of my insight when I went to my first meeting and what I learned. Thank you.

James Valentine, JD, MHS ([04:07:38](#)):

Yeah. Thank you, Don. Thanks for sharing that and great to hear about other approaches like oral rehab really.

Barbara Kelley ([04:07:45](#)):

It certainly gets away from the device aspect and takes it into the coping strategies and things you can do, which is really important.

James Valentine, JD, MHS ([04:07:53](#)):

Absolutely. So I see we have some calls coming in, so want to take us there and as part of our exploration of different treatment approaches, we have Jess from Charlottesville, Virginia, who we'd like to hear from you about your approaches to treatment. Perhaps anything that you've noticed to be helpful. Jess welcome to the show.

Jess Walters ([04:08:20](#)):

Hello! Thank you so much for having me. Can you hear me okay?

James Valentine, JD, MHS ([04:08:23](#)):

I can. Thank you.

Jess Walters ([04:08:26](#)):

Okay. My name is Jess Walters. I was diagnosed with Usher syndrome, which is a rare genetic condition that causes late onset [inaudible 04:08:35] loss. I have a bilateral loss and use hearing aids to communicate and engage with the hearing world. But I wanted to talk to you today, addressing the question of what are the most significant downsides to the treatment. I will preface this by saying that I studied developmental cycle linguistics until I have kind of an unpopular opinion here, but I'm just going to read. There's no documented evidence to support that in the history of medical care in the United States, all treatments for deaf and hard of hearing persons in the United States has been conducted with biased, which intentionally and unintentionally impacts overall quality of life for this population.

Jess Walters ([04:09:18](#)):

The continued practice and perpetuation of stigmatized disease and systemic oppressive actions are the most significant downsides to modern intervention and treatment. In this context, I will define liberalism as prejudice and discrimination toward individuals simply because they are classified as disabled, regardless of whether their impairments are physical, mental, visible, or invisible. And ableism include

aspects of emotions or attitudinal reactions, behavioral practices, direct actions and cognitive beliefs and stereotypes that go beyond general negativity.

James Valentine, JD, MHS ([04:10:01](#)):

Quickly I just I'm interested in hearing if there's a specific personal experience that you have that you want to share, that's where we want to really hear individual experiences with treatment. So I appreciate that you have some broader insights into this, but for today, I'm really interested if you have, like for example a quick example to share from yourself.

Jess Walters ([04:10:30](#)):

Yeah. Okay. So a close example that I have to say for myself is when I was given hearing aids at the age of 15, my physician told me that I was "six." Which implies that I have a deficit, which is to say that I'm broken, which is why I bring up ableism. Because I feel like from the onset of my diagnosis, I was discriminated against. Every speech language pathologist that I have ever encountered or the audiologist I have ever encountered, every medical physician has approached me from this deficit based perspective whereby my deafness is perceived as something disparages.

Jess Walters ([04:11:05](#)):

This has led to very significant questions of self-worth. It has contributed very largely to my mental health. I experienced a lot of suicidal ideation, depression, anxiety, chronic PTSD, and trauma affiliated with a lot of my experiences from being oppressed just by the system.

James Valentine, JD, MHS ([04:11:31](#)):

Yeah. I think-

James Valentine, JD, MHS ([04:12:06](#)):

Thank you so much, Jess. I appreciate you sharing this. And I think we really are glad to have a variety of perspectives shared today. And so I'm glad that you voiced this one for us. I know that there's a range of different experiences and with treatments we've heard both good and bad, but do want to acknowledge that your experience Jess and thank you for sharing that. I also have another caller on the line. We have Joy from California. I think joy we had a chance to talk a little bit this morning, but very happy to welcome you back to talk about any treatment experience you want to share.

Joy ([04:12:57](#)):

Hi, thank you for having me again. So like Jess, I actually also have upward syndrome, which is causes my hearing loss. I use bilateral hearing aids, which helps quite a bit. And one of the lessons that I learned along the way was that I try to really impress upon others with upwards syndrome is not to wait on the hearing aid. I waited on my right ear, which degraded much quicker than my left side. And I have very limited benefit from the hearing aid on that side. And a lot of tinnitus is on that side. And then when I became borderline for my left side, I jumped right on the hearing aid and quickly realized just how much improvement I was getting, because I was finally able to hear those high-frequency sounds that I wasn't given really the benefit on the right side. Mainly because I did it quickly enough that the benefit was still accessible.

Joy ([04:14:07](#)):

The other thing I do is I avoid stimulants to try and keep the tinnitus from becoming worse. I tend to listen to people with my left ear, I walk on their right side. Sometimes I lean in with my left ear. Sometimes I still do the ear hearing, which remarkably actually really works. And then the other I'm a woodworker as well. So I wear completely occlusive hearing protection, which means I have to take my hearing aids out, stick my hearing protection in, which makes it really hard to hear an instructor or anybody at all speak to me. But I know it's so necessary because it's protecting what hearing I still have, to the extent that I'm able. So I guess my answer would be for treatment to look forward to I'm a swimmer, I'm a swim mom as well.

Joy ([04:15:07](#)):

We spent a lot of time in and around water and I can't wear my hearing aids around water, although I've accidentally dove in the pool many times with them in. But it would be so amazing to have a device that I could wear in water and still feel like I could hear and be a part of conversations when we're in those activities. And any treatments that would actually eliminate my tinnitus would be a huge boom because sitting in a quiet room alone and still having a buzzing constantly in your head all day long can be quite stressful. So at night, the other way I accommodate my tinnitus is I read myself till I'm nearly asleep because once my hearing aids are out, my tinnitus gets worse. It spurts rather it's just more noticeable. It's probably the same all day, but I noticed it because I'm not hearing other things. So I read until I'm practically asleep in order to kind of mitigate the sleeplessness that tinnitus can cause.

James Valentine, JD, MHS ([04:16:15](#)):

Sure. Wow. You hit a lot there Joy, but it was all extremely helpful. I heard you loud and clear on your ask for the future about having hearing aids that are compatible with water activities, but you also gave us a lot of insights into current strategies and approaches that you're taking. So thank you again for calling back in. It was great to hear you again. I want to broaden the discussion. I've been focusing us on things that we've noticed that have been successful or helped in living with a hearing loss, but we of course have already been hearing and want to keep hearing about also either things that haven't helped as much, or perhaps they come with a downside. And so to get us thinking about this, we have a polling question. So please pull your phones back out or go to that browser tab, go to [PolLEV.com\HLAA](#).

James Valentine, JD, MHS ([04:17:14](#)):

And we're going to go to a polling question here. Polling for, if we can go to that. Here we want to know what are the biggest drawbacks of your current treatment approaches? Again, thinking across all of those different approaches that you have, that you shared with us earlier and select up to three of what you view as the biggest drawbacks. The options are, A: they're not very effective, B: they have a high cost or co-pay or not covered by insurance, C: limited availability or accessibility, D: they improve your hearing, but not completely. E: they have side effects, F: they require too much effort or a time commitment. G: others aren't cooperative when asked for accommodation, H: some other drawback to your current or treatment approaches, or I: this isn't applicable to you again, because you are not using any current treatments.

Barbara Kelley ([04:18:12](#)):

James, I think this tracks with the other polling questions is that the devices do help. They certainly help quality of life, but not completely to the extent that people would really hope for.

James Valentine, JD, MHS ([04:18:26](#)):

Sure. And while we're having people answer this Barbara, any comments that we've been seeing coming in on the web, things I know we're kind of transitioning things that have helped-

Barbara Kelley ([04:18:38](#)):

Yes we do. I've had a few here on successes. We have Genevieve from Mashpee, Massachusetts. She said, "Both my husband and I have hearing loss, mine more significant. I have a cochlear implant on one side, and he wears a bilateral hearing aids. The words missed in our conversation often lead to total misunderstanding." But I like this next part. She says, "So far, no divorce, 55 years of marriage keeps us together!" So I would consider that a success, right? They have worked it out. We have Arlene from Hackensack, New Jersey, and she says, "As a CI user," she goes on, "I know my strengths and communication strategies and that impacts my choices on activities socially and community involvement." She says, "It's always problem solving." But this one was interesting from Robert, from Finland on the devices. He said, "When I had hearing aids, I bought the programming equipment and programmed them myself." He said, "that was the best money I ever spent." That was the first we've heard of that kind of comment.

James Valentine, JD, MHS ([04:19:50](#)):

Absolutely. Well, thank you for those of you have chimed in on that. I see that we have comments coming in on all of those discussion questions I showed earlier. So want to keep encouraging you if you want to submit those comments, use that comment feature under the livestream. So back to our polling question here, I wanted to give you some time to think about this. It looks like the top choices are that for the biggest drawbacks of current approaches are that they don't improve your hearing completely. And the high cost or co-pay, not covered by insurance, others aren't cooperative when asked for accommodation that getting to some of the non-medical approaches to managing. And then finally, I would say maybe limited availability or accessibility to current approaches.

James Valentine, JD, MHS ([04:20:43](#)):

So we definitely want to hear about those downsides of treatments and how they're not effective in the ways that you need them to be, as we expand into this next discussion. And we'll remind you that you can call in at any time. The phone number is 1.703.844.3231. But first let's go back to our Zoom participants here. And perhaps let's start with Alissa. Alissa, when you were thinking about either treatments that haven't been as useful in terms of being effective or had some kind of a downside attributed to them, what came to your mind?

Alissa P. ([04:21:28](#)):

Thanks, James. My name is Alissa. I experienced sudden single-sided hearing loss about seven years ago. So I spent most of my life with what we consider normal hearing. Initially, the treatment options that were offered traditionally a hearing aid, for example, I had severe to profound loss. So I did not qualify for a hearing aid. There are two additional options. There is a cross hearing aid device for people with single-sided loss and also a Baha or bone anchored device that was offered to me. Unfortunately, with my loss, it was replaced with tinnitus and those two devices don't alleviate the symptoms of tinnitus. So I felt that my only option moving forward was a cochlear implant, which I did pursue. And I now currently have a single-sided implant.

James Valentine, JD, MHS ([04:22:37](#)):

And so you described the need to get the cochlear implant because of the tinnitus and that's resolved with the cochlear implant?

Alissa P. ([04:22:42](#)):

Tinnitus is masked when I'm wearing my external processor. So when I do remove it in the evening to change the batteries, that sort of thing. I do notice that it does reappear, but as previous callers have mentioned, there are coping mechanisms for tinnitus, which I'm happy to touch on as well.

James Valentine, JD, MHS ([04:23:07](#)):

Sure. And just to understand that benefit of as you described it, masking the tinnitus, what does that mean for you and your life when it's masked?

Alissa P. ([04:23:21](#)):

It means everything. To be honest, as many can attest to the tinnitus is at times crippling, isolating, frustrating. So as I said, the pursuit of the implant I felt was my only option. And without it as Lise said, she couldn't live without it. I'm not quite sure where I'd be without it.

James Valentine, JD, MHS ([04:23:58](#)):

Sure. Any specific, you know you mentioned that it was isolating to have it, is there an example of something...

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James Valentine, JD, MHS ([04:24:03](#)):

... And that it was isolating to have it. Is there an example of something you've been able to do now as a result of having the tinnitus reduced or masked?

Alissa P. ([04:24:12](#)):

Yeah, absolutely. I'm much more comfortable attending social gatherings, having the implant now. And when I don't have my processor on, I have found a white noise application on my phone that I've been able to match with a specific tone of tinnitus that I experience. So I'd recommend, there's different types of noise that I've learned and white noise and brown noise and pink noise, and you can identify the certain sound that closely resembles it. And by playing it in the background, I am able to even that out for myself. So my normal hearing, my normal side, will normalize that sound for me.

James Valentine, JD, MHS ([04:25:04](#)):

Sure. And in what settings is that helpful? I would guess perhaps at home, but any other settings that, that management strategy is helpful with the white noise?

Alissa P. ([04:25:17](#)):

I would say at times at work, I have played it when it's been quiet. Even though it is relieved with my implant, if there is no sound around me for the processor to take in, I can feel that it's returning, trying

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to find sound for me. So at work, I have put it on at a low volume. But otherwise, mostly out of the house, I usually have my processor on. And so I don't need those coping techniques.

James Valentine, JD, MHS ([04:25:51](#)):

Sure. Well, thank you so much for exploring that and letting me probe a little bit there to better understand. I want to invite Gloria into the conversation on the same topic of thinking through any experiences where a treatment has not been helpful or it has some downside that you'd like to share with us.

Gloria H. ([04:26:13](#)):

Hello, I'm Gloria, from Alexandria, Virginia. And my hearing loss came as a result of chemotherapy about five years ago. I was a little reluctant to get the hearing aids that they said I needed, but I realized that I did need them. My hearing loss is more on the left side, more profound on the left side than on the right. But I do know that the hearing aids, when I wear them, they do help. They don't do everything, but they do help me.

Gloria H. ([04:26:51](#)):

My husband often tells me to put them on because I don't usually wear them at home. When I go out, I put them on. But the downside is that they do help, they don't do everything. In personal conversations, I notice that I have to lean into the person in order to understand or hear what they're saying. If a person turns their back to me and talks, I can't hear it, and I have to ask them to please turn around. But again, the bilateral hearing aids have been working. I think they're out of warranty now, so I need to see about getting something else. I have an appointment with an audiologist soon and we'll see what happens then.

James Valentine, JD, MHS ([04:27:36](#)):

Sure. Well thank you for highlighting both where they're helping and where some of the limited scenarios that are more limited in their helpfulness. So thank you so much, Gloria. I see we have a phone caller who wants to speak to approaches to treatment. We have from Ontario, Canada, who has tried a number of different things. So I would like to welcome Michael to the program.

Michael ([04:28:06](#)):

Hello, good afternoon.

James Valentine, JD, MHS ([04:28:07](#)):

Hi, welcome, Michael.

Michael ([04:28:10](#)):

Yeah. Thank you for having me. Can I just tell you what I'm currently faced with right now?

James Valentine, JD, MHS ([04:28:18](#)):

Yes, please do. We'd love to hear that.

Michael (04:28:20):

Okay then. So just to give you a snapshot of my circumstances and tried and true methods that aren't exactly cutting it and what I'm hoping for. So just to give you a bit of a background, I have noise induced hearing loss that has gotten worse over the year due to some unfortunate additional noise exposures, including the last one was a loud movie theater and a loud MRI that kind of finished me off. So what I'm faced with right now is moderate to severe high frequency hearing loss, borderline moderate severe high-frequency hearing loss. My audiogram looks like a ski slope. And accompanying that noise-induced hearing loss, I've got moderate, borderline severe tinnitus that the last time it was matched, because at my hearing test, they'll play it back, they'll try and match my tinnitus tone and they'll try and raise it to a volume where it actually mingles with my tinnitus.

Michael (04:29:29):

And so my tinnitus based on that matching, my tinnitus is currently about 65, 70 decibels loud. So that's how loud my tinnitus is. I can hear it over a lot of things, including mild neighborhood city traffic. Accompanying my tinnitus, I've also got hyperacusis. And for the listeners who don't know what hyperacusis is, it's a decreased sound tolerance. Something gets thrown out of whack when your auditory nervous system gets damaged enough. And all of a sudden, I get earaches from sounds and noise is that other people might be able to handle. Like if a dump truck drives by me and I'm walking on the sidewalk, I might be looking at painful earaches for the next day or two from that. I can't go to concerts anymore, I can't go to movie theaters anymore, even with earplugs because the average concert or movie theater is over 100 decibels these days.

Michael (04:30:27):

And even the best earplugs, I've got custom earplugs and they only offer a certain degree of protection when you're in 100 decibel environment. So, I've had to give up things that I used to enjoy, like concerts and movie theaters. Another thing I'm suffering from, which is a consequence of having the hyperacusis, is something called tonic tensor tympani syndrome. And for the listeners who don't know what the tensor tympani muscle is, it's the muscle that contracts the eardrum to protect your auditory system from loud sounds. And when you have something like hyperacusis, this involuntary reflex mechanism starts going off with the tensor tympani muscle where I have days where, like I said, if I'm exposed to a loud sound just from going around, it could be like a security beeper in a grocery store, something like that, within a day or so, my tensor tympani muscles have tightened up.

Michael (04:31:42):

I get pressurization problems in my inner ear where it feels like I'm descending in an airplane and I'm getting that pressure and that popping sound in my ears and it doesn't quite subside. So just a whole slew of things, all stemming from that hearing damage. I consider the tinnitus, the hyperacusis and the tensor tympani syndrome, they all stem from a common denominator, which is the damage to my auditory system. So the methods I've tried to address all these things, it's pretty complex because the problem is, is if I just had the hearing loss to contend with, hearing aids would be great. But even though I have hearing aids that are sitting on my desk, I can't wear them because of my hyperacusis.

Michael (04:32:38):

Because with hyperacusis, you're already sensitive to loud sounds. So the last thing somebody wants to do with hyperacusis is go around with hearing aids, because of if loud sound goes off, it's going to be

amplified even more by those hearing aids. So I'm kind of stuck dealing with my hearing loss on my own without the use of hearing aids because of my hyperacusis. And for the hyperacusis, if I go into a loud public area, even a loud crowded restaurant, I wear my custom earplugs so that I don't pay for sitting in a crowded restaurant, by getting earaches two days later. So that's how I contend with that.

Michael ([04:33:27](#)):

The other problem that I'm running into is just a sense of isolation that comes from having to deal with all that. I tried tinnitus retraining therapy, which I'm sure other listeners have tried. The thing is, is to a degree, it does help. But when you've got tinnitus at 65, 70 decibels loud, it comes to a point where you literally have to learn to get beyond that with your own willpower, because those makers only work so much, depending on how loud your tinnitus is. That's what I found. And I just want to let the listeners know, what I found helped me the most when my tinnitus was milder was broadband pink noise studies have shown that the broadband pink noise tends to work best in terms of habituating to one's tinnitus, depending on how severe it is.

Michael ([04:34:36](#)):

So the final thing I want to go over with you, which I know you're interested in knowing, is what my hopes are for the future.

James Valentine, JD, MHS ([04:34:43](#)):

Yes.

Michael ([04:34:43](#)):

And so if I can just be candid, and please, I just want all listeners and you hosts to take my comments with a grain of salt. I'm not trying to sound cynical or anything, but devices such as hearing aids and tinnitus retraining therapy, and some of these other devices or whatever, or if they come up with oral medications to lower tinnitus, Valium already does that, but you got to be careful not to get hooked onto Valium and or any of those benzodiazepines that can help lower the volume level of your tinnitus. I think the thing that's really going to make a difference in people's lives is what certain companies that I've been following, what they're doing in terms of regenerative medicine, finding ways to get the hair cells in the inner ear and the damage done to the auditory nervous system, encouraging it to repair itself, encouraging hair cells to regenerate.

Michael ([04:35:53](#)):

I know I can't mention specific companies on air because I don't want to come across as endorsement. I get it. But there are companies out there that are on the forefront of addressing hearing loss and hearing damage at the root, whereas devices just kind of deal with the symptoms as opposed to the root damage that's causing all this. And the thing is, is I was already told by my ENT specialist, who I see at Sunnybrook Hospital in Toronto, major research institution, if my hearing damage or my hearing loss were to get any worse and I was a candidate for cochlear implants 10 years down the road, if I want to hold off for anything regenerative, I would have to hold off from a cochlear implant.

Michael ([04:36:50](#)):

Because once your cochlear tissue is damaged by an implant, they can remove the cochlear implant. But the chances of that tissue being a sponge or being susceptible to anything regenerative that is trying to interact with that tissue, scar tissue is going to hinder that. So I'm holding out for the regenerative stuff that they're working on right now and receiving a lot of funding for. Because right now, short of a miracle, I think the regenerative medicine, for me personally, and I would hope for other people, is kind of like putting a lot of hope in that.

James Valentine, JD, MHS ([04:37:40](#)):

Yeah. Thank you, Michael. I think you really, in describing your constellation of symptoms and health effects really helped us understand why it is you're seeking something that's disease modifying at its core. I think based off of your individual experience, it makes a lot of sense why that's your treatment goal for the future. But I do appreciate you sharing the things that you've tried. I think that was really helpful. I do know that we have comments coming in on this topic of treatments that have not, gaps I guess we can call it, and downsides. So I want to be sure to make sure we share some of those coming in. So I'll turn to Barbara to do so.

Barbara Kelley ([04:38:30](#)):

Thank you. I'm very glad that Michael touched upon hyperacusis because we've heard that more than once today and it's coming up in the comments a lot, James, and that is a super sensitivity to sound and the pain, the actual physical pain that comes with hyperacusis. Linda from Gainesville, Florida, says, "Tinnitus and hyperacusis often accompany hearing loss." And she said, "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." And she has not found any effective treatment for the hyperacusis and the tinnitus. We also have somebody who tried—an anonymous comment—this person said, "I have tried psychological help and sound therapy, although these treatments have been of limited use."

James Valentine, JD, MHS ([04:39:31](#)):

Sure. Well, thank you so much. And please continue sending in those comments and calling in. We've really been enjoying the comments we've been hearing so far. I want to take one more caller before we head into our final question for you about future treatments. But I see we have Linda from Wisconsin who has a few different treatment experiences herself to share. So Linda, I would like to welcome you to the program.

Linda ([04:40:12](#)):

Thank you. I appreciate the opportunity to be here. So I have a cochlear implant. I also have a hearing aid. I've had normal hearing growing up, but just in the last 20 years, I've lost hearing. So I've tried about everything that is available to try, but I've also learned sign language because captioning, I have a reading disability, so captioning is not helpful to me. But the thing that I find to be a consistent problem, regardless of the technology that I use, is listening fatigue and just always being really, really tired. I'm also a scientist, so I know that there are tests or ways of testing things that our consumers do not necessarily even know that they are doing or aware of.

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Linda ([04:41:12](#)):

So there are ways to test for fatigue, and I believe that it's important that manufacturers of devices of all kinds go ahead and develop those tests and that they communicate the results of those tests so that people can make informed choices. When I try to choose a cochlear implant, having some information about how tired I'm going to be, as I walk into life, it's really important. That fatigue affects my work, it affects my relationship. It affects basically everything I do in my life. It's really important that people understand what they're buying before they buy it. Thank you.

James Valentine, JD, MHS ([04:42:05](#)):

This is a really insightful comment, Linda. And so I want to follow up with you for a second, if I can. I think hearing that you would want information and it would be helpful to you to know the impact that a treatment would have on fatigue, or as you described it, hearing fatigue. How would you, I guess in your own words, describe what you would be looking for in terms of reduced fatigue? I guess what I'm trying to ask is, what amount of improvement in that fatigue would actually make a difference in your life?

Linda ([04:42:55](#)):

So at this point, it depends upon at what stage and what devices I was using. So as the hearing aid declined in effectiveness, the fatigue increased. And so there were really times when I had a limit on the number of hours I could listen in a day. And I had to be very careful about the environment I was in. So then when I got the cochlear implant, listening was easier. But as the other ear continues to decline, it becomes more difficult to hear, right? There was a point when literally, if I listened for hours a day, I was so tired I couldn't do my job.

James Valentine, JD, MHS ([04:43:48](#)):

Wow.

Linda ([04:43:50](#)):

Thankfully, I was within a few months of being implanted. So I was able to keep my job. But you have to be able to walk into life, you have to be able to listen six to 10 hours a day without being fatigued.

James Valentine, JD, MHS ([04:44:09](#)):

Yes.

Linda ([04:44:09](#)):

And when you are limited to a couple hours, you have serious limitations on the kinds of things and kinds of relationships you can have.

James Valentine, JD, MHS ([04:44:24](#)):

Sure. This is extremely helpful, so I want to thank you so much, Linda, for sharing that. And what just sticks out to me is there's a certain number of hours of listening, of hearing, that you can do until you're too fatigued to do other things, much less continue listening and hearing. Thank you so much for that insight. I think it's a perfect transition into our final polling question, not only of the session, but of the day, which is, "What is it that you are looking for, from a future treatment?" We've been starting to hit on this, but we'd like to invite you to pull out your cellphones, open up that tab one last time to

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PolLEV.com/HLAA and answer this last polling question we have for you, which is asking, "Which aspects of your hearing loss would you rank as most important for a possible new drug or device treatment today?" We're going to ask you to, like some other questions, select top three.

James Valentine, JD, MHS ([04:45:29](#)):

So the options here are A: improving hearing, B: hearing restoration, C: decreasing background noise, D: helping with tinnitus, E: helping with the ability to speak, F: improving balance, G: slowing or stopping progression, or H: some other aspect of hearing loss that you would rank as most important for a possible new drug or device treatment today. Think about this for just a moment and we look forward to seeing your results. And think about the why of this, which is to say, think about why do you pick this particular aspect of hearing loss and what change would you need to see in which whichever of these aspects that you're selecting, in order to experience a benefit, or what information would you need to see to make you decide to use that next new therapy?

Barbara Kelley ([04:46:30](#)):

James, I think this poll, on one hand, it's no surprise whatsoever. But on the other hand, it really pinpoints what's important to people. And it is surprising. We have the majority here wanting complete hearing restoration, where other people are just looking for improvements. And of course, tinnitus remains important.

James Valentine, JD, MHS ([04:47:05](#)):

Yes. And the ever-present decreasing of background noise, which we've heard so, so much about today.

Barbara Kelley ([04:47:10](#)):

Yes.

James Valentine, JD, MHS ([04:47:12](#)):

And then we hear others talking about, even as a top three thing, some kind of improvement, but just the slowing or stopping of progression. We know, of course, like everything we've talked about today, these are so personal and individualized in what people are looking for and what they've experienced, what they've tried, how it's helped, how it hasn't, and like all of those other topics, when we're talking about future treatments, similarly, it's very personal, depends on where you are in your hearing loss journey and just even your own personal preferences.

James Valentine, JD, MHS ([04:47:50](#)):

So that's what we really want to hear about now, as we go to the final part of our discussion, which is now to focus on what it is you want to see from future treatments. So with that, I'd like to invite you one last time to call in, to help share what it is your looking for from future treatments. One last time, that phone number is 1.703.844.3231. And again, you can also write in with comments at this point. There's that same comment feature that's been available under the live stream today. But I would like to get us started with our Zoom panel. I have Russ and Don who want to share some of their perspective. So why don't we start with you Russ.

Russ M. (04:48:38):

Thank you. Future treatments. A few years ago, I was asked by an organization, I can't frankly even remember which, to prepare a video. And what they were asking me is, talk about three problems associated with your hearing loss that are most serious. And I said, "Well, that was easy. The three problems are basically noise, noise, and noise." I'm defining noise pretty broadly to talk both about unwanted environmental noise, as well as speech that you really don't want to hear, because it interferes with what you do want to hear. With that in mind, one area that strikes me for future development, that to me is important, is better directional microphones. Most good top of the line hearing aids have options to decrease unwanted noise, usually focusing on what's in front of you and suppress what's on the sides and the back. They work to some degree, but frankly, not terribly well. I think some work on that would be terrific because I noticed that I, as well as many, many other people today have complained about noise. That's one area.

Russ M. (04:50:08):

The second area that I think I would love to see some work on is captions, and particularly it's latency. For people like me who can hear, and actually I prefer to hear rather than to use caption. If I can hear sound, I can process it much quicker and much better than I can the written word. But the problem is, with latency, I hear things and I look at the captions and what I'm seeing in the captions is not what I'm hearing. Focusing on two things simultaneously, for me anyway, is a huge problem.

Russ M. (04:50:51):

The third area I'd love to see some improvement on is music. Hearing aids and cochlear implants have been made specifically and with malice of forethought in order to focus on speech. And that makes perfect sense to me. But loss of music is a huge problem for a lot of people. That could be part of being human. [inaudible 04:51:18] done on that to make that better. Thank you.

James Valentine, JD, MHS (04:51:25):

Thank you, Russ. That was such a clear articulation of some very specific, as well as a broader needs. We got it, it's sound, sound, sound. Thank you for that. I want to take it over to Don. What are you looking for when it comes to a future treatment?

Don D. (04:51:47):

Thank you. Today, I think I would like to see a little bit more research in the many devices and many apps that are out there. I've been involved with hearing loss for over 50 years and invariably, I'll go to a convention or go to a store and I'll pick something up, get home, try to put it together and it doesn't work. \$200, \$300 out the window. There's new consumer report advocate that can guide folks. I'll give you an example. Right now, we have going on a lot of products being sold over-the-counter, they're amplification devices. It would probably work for somebody with mild to moderate hearing loss, but they're not going to touch somebody with a severe or profound loss. And some of these devices, they can cost from \$25 to \$100 or even more. So I think we need to have more consumer-based education as to not only what's out there, but what is out there that's reliable and it works for many people based on the severity of their loss and other conditions that they would look forward to.

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Don D. (04:53:09):

Hearing loss is very individualized. Everybody has different expectations. Sometimes we have to not look at the grand cure all and expect 20/20 hearing from some aspect in the future. I think even with a transplant or hair cell restoration, you still might have some limitations in terms of what you have to work through. So just expect that. It takes a lot of hard work, it takes a lot of knowledge, it takes a lot of going back to your peer group and sharing that knowledge so that they would know what your experiences are. And I really think that this education, self-advocacy, they're the keys. We know what's out there in the Americans with Disabilities Act, but sometimes we don't say it and sometimes we need to.

Don D. (04:54:06):

Way back in the beginning, my first year or second year of hearing loss, I tried to hide it. I didn't want everybody to see it because I was afraid somebody would report me as not being able to hear and all of that, and discharge me for the Marine Corps. But as I grew more knowledgeable about this whole process and more realistic, I recognize that there's a lot I can do, even without a lot of technology, that's going to help myself, by my placement, by my choices, by my self-advocacy and by my continuing to learn about this thing we call hearing loss. Thank you.

James Valentine, JD, MHS (04:54:49):

Thank you, Don. Want to see, just give me a quick wave of the hand if Lise, Gloria, or Alissa, you have anything to add before we let our Zoom panel here go. Yes, Alissa.

Alissa P. (04:55:05):

I would agree completely with Don and his mention of education. I'd like there to be a more holistic approach when speaking with doctors or hearing health care professionals. In my own experience, there weren't many options, which is fine, but you're left to your own devices at that point and recommendations, education, therapies do have a very positive result. I did receive cognitive behavioral therapy for myself, anti-anxiety medications for a brief period. There are other ways to approach it from different angles. So thank you.

James Valentine, JD, MHS (04:55:57):

Sure. Thank you, Alissa. And Lise, I saw you raise your hand as well.

Lise H. (04:56:08):

Sorry, I had the delay here. But just quickly, when I looked at that poll and I saw all the people looking at hearing restoration, I said, "Yes, I'm in." Because here's the thing, when I had my hearing loss, immediately the first thing I wanted was a speech-to-text app. Back 40 years ago, 35, it was a dream, it was a total dream. So, well, maybe we can dream on. I think a lot of people are realistic in saying, "Right now, we don't have hearing restoration, we've got to be realistic. Let's think about noise reduction. Let's think about improved hearing." And I agree, and you have to educate. We live in the real world, but let's dream. Hearing restoration, for me, if I could take a pill today and do it and have my hearing restored to what I remember or even better, I would do it.

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Lise ([04:57:02](#)):

[inaudible 04:57:00] or even better. I would do it in a heartbeat. So I think that's why you're seeing that great big. People are saying, yes. That's what I'd love and we'll dream. Maybe it won't happen real soon, but whenever it happens, I think you'll have a bunch of people ready to do it.

James Valentine, JD, MHS ([04:57:19](#)):

Yeah. Thank you, Lise. I want to thank our entire Zoom panel for joining us. We're going to take some more phone calls and have some more written comments shared, but I want to let you all go Thank you for hanging with us throughout the program. Lise what a great final parting comment. I think it really highlights that these aren't necessarily either ORs. They can be ands. We can want both near term, and long-term. Where smaller, more iterative change. As well as that shooting for the stars change, like speech to text was many years ago.

James Valentine, JD, MHS ([04:57:59](#)):

So want to thank you all for your contributions. And now I see we have a couple of phone callers in the queue. So want to definitely go to the phones and hear about what it is that our audience is interested in, in future treatments. Let's start with Ali from San Diego. Again, I think this is one of our morning callers. Glad to have you back, to help weigh in on this important topic. So welcome back to the program.

Sheila ([04:58:29](#)):

Hi James. Thank you. Well, the previous caller, Michael, pretty much almost had the identical response that I was having. The drug restoration basically with his tinnitus. Tinnitus, same with me. I have severe tinnitus and this hyperacusis, which I'm now learning about because this is all new to me. I'm realizing that is a major issue for me as well. Even just having some degree of hearing restoration in my left ear. Again, I have profound hearing loss in my left ear. My right ear is normal hearing from a Mumps virus. Just having a drug restoration. I thought about some of the other hearing aids now, that really don't work very well. Bringing one sound from my left ear, into my right ear. It doesn't really help. There's a Baha bone anchor hearing aids, or some cochlear implants that I'm just not ready to get, because I feel like that's not actually getting to the fundamental issue or fundamental cause of my hearing loss.

Sheila ([04:59:47](#)):

Which I feel like medical drugs that they're developing now that will actually restore those hair cells. Even if it's just a little bit simpler, I may still have to wear a hearing aid, but I feel like that will have a multiplier effect in that it could reduce the tinnitus. It could improve my balance and some vertigo symptoms. I'm really following those, those aspects for me. So I really hope those progress, and I'll be able, hopefully, to be part of the study. Which I'm not yet, because of my complete hearing loss. I'm very helpful with those in the future.

James Valentine, JD, MHS ([05:00:35](#)):

Yes. Thank you, Ali that's, I think you're very articulate in explaining how this type of hearing restoration might be able to help even with, not the direct hearing loss, but some of those other accompanying symptoms as well. I really appreciate that. Shout out to anyone who volunteers or is interested in volunteering in clinical trials. We couldn't advance any new treatments if it wasn't for those of you who

are willing to test out and try those investigational treatment approaches. Since we heard, you mentioned that Ali, I would give a shout out to all of you in the audience who participate in clinical research. I see we have Sheila from Ohio who also wants to share some of her preferences for future treatments. So I would like to welcome Sheila to the program.

Sheila ([05:01:36](#)):

Well, thank you. My biggest concern right now is, my hearing loss continues to get worse. I have nerve damage due to measles when I was in first grade, and I'm now almost 70. Each year my hearing gets worse, I got a get some ways to keep my hearing from getting worse. Even restore a little bit of it. It's frustrating. Especially this last year with wearing the masks, in COVID, because I lipread, as well as wearing hearing aids. The hearing aid doesn't help, because I do primarily hear by lipreading. I just don't want my hearing to get worse.

James Valentine, JD, MHS ([05:02:45](#)):

Yes.

Sheila ([05:02:45](#)):

I guess that's all I have to add.

James Valentine, JD, MHS ([05:02:52](#)):

That's important. You're not alone. Sheila. I saw a number of people pick that in that polling question of slowing and stopping progression. Thank you for voicing that. Could you tell us a little bit about your progression? You mentioned that your hearing is getting worse. So we understand a little bit about where you are right now,

Sheila ([05:03:20](#)):

The closed-captioned isn't keeping up with what you're saying.

James Valentine, JD, MHS ([05:03:33](#)):

I'm so sorry about that. [crosstalk 05:03:34]

Sheila ([05:03:35](#)):

Okay. That's good enough. The hearing aids don't help with facemasks. When I'm trying to hear, with someone with the mask. I've had a very difficult time with businesses and other institutions. We want to make accommodation. So I would really like to have it by hearing loss slowed down. Or even get them back.

James Valentine, JD, MHS ([05:04:05](#)):

Sure. That's very helpful. Thank you so much, Sheila, for sharing your thoughts about future treatments. I think we have time for one more caller, and then we're going to check in with some of these written comments that I've seen have been coming in. So we have Robert from California who wants to share some of what he's looking for in future treatments. So welcome to the program, Robert.

Robert ([05:04:30](#)):

Yes, thanks for having me. I've been successfully treated with bilateral cochlear implants. I actually do reasonably well with them, but I'm a former musician and I really would like to be able to hear music better. I read an article by a science writer, about how he went to a person who programmed hearing aids, and developed chips for them. He asked them if he would build a chip so that he could hear music again. They were successful. So I'm curious about why that can't be done now for the rest of us.

James Valentine, JD, MHS ([05:05:23](#)):

Sure. I think that a very concrete and important ask for future treatments. Maybe Robert, you can tell us a little bit in terms of what degree of music you can hear now, if any? How much improvement do you need in order to hear music? If that makes sense.

Robert ([05:05:52](#)):

Okay, the range of music is from like 50 Hertz to 10,000 or more. And the speech range is much more narrow. So I'd like to be able to hear. I can hear quite a bit of music now. I can hear classical music and I can discriminate an oboe from my flute, and cello from a violin, that sort of thing. I don't really hear the bass like I did when I played, I don't hear the real high pitch sound and they're distorted. I'm curious about getting a little more range so that I can.

James Valentine, JD, MHS ([05:06:37](#)):

Well, I'm glad I asked that question, Robert, because actually that was quite helpful. Thank you so much for calling in and sharing your preferences and hopes for future treatment. I know we have a number of things from the web. So Barbara, feel free to take us through.

Barbara Kelley ([05:07:01](#)):

Sure. Thank you, James. I do have some. Dan from Brattleboro, Vermont, says "The only solution I am interested in is something to regrow the damaged and missing cells." Then I have a couple of comments on technology. Ray from Hialeah says, "One technology that I'm really looking forward, is the ability to use the brain to segment and segregate the speaker in a group that I'm listening to. I have heard of some research on using brain waves to feed into the hearing aid or cochlear implant, to be able to focus on a particular speaker, like normal hearing people can." Then, Lisa from San Diego says "A hearing device that allows for hearing in the water would be amazing." So we have some on the restoration aspect for the future, and then we have some who want some device improvement. I think you made a great point, that it might not be either or, it could be a combination.

James Valentine, JD, MHS ([05:08:01](#)):

Yes. I think that's kind of the perfect recap before the official summary of this session. Which has really focused on helping us identify where the current treatments are helping. Where there is some gaps, and unmet medical needs that exists. Seeing the range of things that this community is looking for from future treatments. The wide range of helping expand the range of what can be heard using devices. So we can hear music, or better interact with our children. To being able to have hearing regeneration that maybe can actually help with some of those other symptoms that are associated with hearing loss.

James Valentine, JD, MHS ([05:08:51](#)):

At this point we are concluding the part of our agenda. Where we've been getting our input. I know there's so much we could continue to cover. We could probably do this for days. I think we really accomplished a lot today. In terms of bringing forward and having you all paint a picture of what it is to live with hearing loss and the other symptoms associated with hearing loss. Really help us understand what that means in your day-to-day lives. Then in the afternoon session, really expand on, build on that and help us understand the landscape of current treatments, and what it is you're looking for from the future.

James Valentine, JD, MHS ([05:09:35](#)):

As your meeting moderator, I have to say you all have done a tremendous job. Not only for our colleagues at the Food and Drug Administration, but also those that are doing research in this space, developing products in this space. Even those that are providing care to really fill in an area. We have some information to understand, but I don't think anyone fully appreciated what it is to live with hearing loss, until they heard from you today. I know it's not easy to talk about the negative aspects. We always want to focus on what's helped, what's worked.

James Valentine, JD, MHS ([05:10:19](#)):

How we persevere, and this is definitely a community that perseveres. I heard that loud and clear, but I also know that what I heard from you is that you do have needs. You have needs for yourselves, for your parents, for your spouses, for your children, maybe who haven't even started experiencing hearing loss yet. So for that, I just want to give you a heartfelt, thank you, for digging deep and sharing those personal stories. We could not have had the impact that today we'll have without each of you being brave and doing that. So without further adieu. I now get to turn it over to our speaker, who's going to provide summary remarks.

James Valentine, JD, MHS ([05:11:03](#)):

It's an impossible task to try to summarize this entire day, but I know he's the best person to try to do this. It's my friend and colleague Larry Bauer. Larry has been involved in research and product development for a long time. He was in clinical research at NIH for 17 years. He then went to FDA where he co-founded the rare diseases program within the center for drug evaluation and research, where he worked for 10 years. I've been fortunate enough to have him as my colleague at the firm for the last several years, working in patient-focused drug development. So without further adieu, Larry, take it away.

Larry Bauer, RN, MA ([05:11:48](#)):

Thank you so much, Barbara and James, like you said, I'm going to try to give a high-level summary of the day and just a few minutes here? Please forgive me in advance for any key points that I might miss. They are important and just know that everything will be put into the Voice of the Patient report. Especially anything that I might've missed. So our day today started with an opening by Barbara Kelley, who is the executive director of the Hearing Loss Association of America. This was followed by a presentation from Dr. Gavin Imperato.

Larry Bauer, RN, MA ([05:12:20](#)):

He's from the FDA Office of Tissues and Advanced Therapies. Dr. Imperato shared how important patient-focused drug development meetings are and the value that they have to the FDA to learn from the experts, who are people living with hearing loss and their care partners, and to try to help facilitate treatment development for hearing loss.

Larry Bauer, RN, MA ([05:12:43](#)):

Following Dr. Imperato. We heard from Dr. Frank Lin, who comes to us from Johns Hopkins and is an expert in this area. He described sensorineural hearing loss as a decrease in sound sensitivity and a distortion in sound encoding. He said that there's 38.2 million Americans who are aged 12 years and older, have hearing loss. That these statistics get worse, as people age. Pediatric hearing loss has implications for impacting critical learning skills. He talked about how hearing is the foundation for development of cognition and fact and social interaction skills.

Larry Bauer, RN, MA ([05:13:25](#)):

Adult hearing loss, he also talked about how that's a risk for dementia brain aging, higher health costs and impaired physical functioning. Hearing loss in mid and later life are identified as the largest potentially modifiable risk factor for dementia. Which I thought was just incredible. I had never heard that before. He said that hearing loss treatments can impact social functioning and long-term risks for dementia.

Larry Bauer, RN, MA ([05:13:52](#)):

He talked about what the current management strategies are. These are assistive technologies like hearing aids. As well as cochlear implants. Then he closed with talking about some novel approaches, such as alternative health service delivery, like telehealth. He talked about the importance of direct consumer over-the-counter hearing aids and different innovations in amplification strategies and signal delivery.

Larry Bauer, RN, MA ([05:14:19](#)):

So from there, we moved into our first panel of the day. This was a panel where we asked people to talk about the symptoms of hearing loss, and what the impacts of those symptoms are on their lives. The first panelists we heard from today is Roxana who began her hearing loss at age 25, from an unknown autoimmune disease. It started with high frequency sound loss, but then progressed. She described the challenges of being in the business world and having progressive hearing loss. She stopped going out with friends and described the stigma of always having to explain, to hearing people that she has a hearing loss. She described her hearing loss as a constant loss, and she has grieved at every step that she has decreased in her hearing function. And she says that hearing loss is the invisible disability because no one seeing you knows that you have it.

Larry Bauer, RN, MA ([05:15:13](#)):

Following Roxana, we heard from Tim, who's had a hearing loss since birth and had hearing aids very early in life. He described the difficulties going through the teenage years and how he felt so different from the other kids. He experienced daily bullying and being mocked by classmates and tried to hide his hearing aids with long hair. He had speech therapy all the way through high school, and he said dating

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was defeating. He felt bad about his pronunciation of words, Tim postponed getting a second hearing aid, but when he did this, because he had waited, his brain couldn't interpret the sounds right away. He says that speaking on the telephone is just torture. One of the outcomes of all this is that he feels fatigued more intensely and worries about getting older. He says he socializes less because he needs more alone time just to reset. He said, it's exhausting having to ask people to speak more slowly or loudly all the time.

Larry Bauer, RN, MA ([05:16:12](#)):

Following Tim, we heard from Katherine who stated that her hearing loss started at age 30. She just woke up one day and found that she was deaf in one ear. No cause had ever been found. She says she can hear sound, but has trouble distinguishing speech. Her hearing loss has had a huge impact, especially this past year when her husband was hospitalized during COVID and all of the staff had to wear masks, so she couldn't lip read. It had a big impact as well on her writing career. She was devastated when she had to take an early retirement due to the impacts of hearing loss. She worries if her children will trust her with future grandchildren because of the hearing loss, the most frustrating thing about my hearing loss, she said is that despite having the most sophisticated and most expensive devices, I still can't hear.

Larry Bauer, RN, MA ([05:17:05](#)):

Then we heard from Anna who has progressive genetic hearing loss in both ears. Anna is an anesthesiologist, and described the daily challenges in the operating room and at work. Work meetings and hearing casual conversations, wearing masks for her once again has had many challenges and is an impediment to lipreading. She wishes there were clear masks at the hospital because these would be a great benefit to her, but her hospital has not made this accommodation for people with hearing loss. She worries what the impacts will be on her job as the hearing loss progresses, which she knows it will, especially because she needs to hear certain alarms and beeps while she's working in the O.R. She also struggles at restaurants and noisy places. Anna says, I also worry about how my hearing loss will impact my ability to communicate with family and friends as it becomes more severe. Finally, for panel one, we heard from Jake who had sudden permanent hearing loss at the age of 18, due to sound trauma from a hunting rifle, going off next to his head without using a sound blocking earplugs. He also developed sound sensitivity, which we have heard from several people, and tinnitus, which he says those two things are actually the worst part for him. After the accident happened, his doctor told him that nothing could be done. Jake said, "The gravity of the situation completely emotionally overwhelmed me." I had this realization that my life, as I knew it was basically over. That this now was my new reality. He eventually also developed balance issues and migraines. He feels that there's an invisible barrier between him and his family and friends, and he feels isolated. Jake said "It really feels like I'm sort of watching everyone else live their lives while I'm stuck in place, hoping maybe one day to return to normal life. It takes a toll on you." So overall people identify trouble hearing, especially when there are background noises. That came up again and again.

Larry Bauer, RN, MA ([05:19:15](#)):

One of the learnings for me was the incredible fatigue that people develop because of all the energy it takes to try to listen, as well as the extreme social isolation that came up again. Some of the worries people had included dementia, workplace issues and losing social connections. In the afternoon, we moved to panel two, which focused on treatments, what people are currently doing to try to manage hearing loss, as well as what they might like to see in the future.

Larry Bauer, RN, MA ([05:19:47](#)):

Our first panelist was Zina. She talked a lot about her intensive speech therapy that she had as a child, which helped her to learn language skills. Zina is in medical school, and has many challenges along the way. This included the need to use a stethoscope, because they're all designed for people who hear well. She said, "People with hearing loss are grossly underrepresented in medical careers." She was repeatedly told she could not be a physician. In almost every educational setting, she said, "I have been an underrepresented minority and had been the first person with hearing loss that my colleagues and instructors have ever encountered."

Larry Bauer, RN, MA ([05:20:28](#)):

Next, we heard from Brenda who has an inherited hearing loss and was diagnosed at age 19. She uses a combination of cochlear implants and hearing aids. She has tinnitus, that's required bilateral hearing aids. She described what the difficulties of cochlear implantation surgery are, with a long adjustment period incisions behind the ears. She would like to eventually see a completely implanted device. She uses Bluetooth technology and closed captioning to assist her. She has many effective family members, including all five of her grandchildren. And she would like to see progress made in the development of a gene therapy to help these youngsters.

Larry Bauer, RN, MA ([05:21:11](#)):

Next we heard from Mike who said that he lost his hearing due to otosclerosis in his early forties. He had surgery on both ears, but the hearing loss continued to progress. Despite the surgery, he described the challenges of hearing when there is noise, and then the impact on trying to socialize in group settings. He said he would be happy to enroll in a trial that was exploring regrowth of inner ear hair cells. We heard that also, as a theme today, people would like to see regeneration of hair cells. He also shared some of the impacts of hearing loss on his mood, including depression and anxiety.

Larry Bauer, RN, MA ([05:21:49](#)):

Next, Veronica talked about how managing her hearing loss is a daily task. She had hearing loss that was related to several vertigo attacks and has trouble with balance. She tried to use steroids in the initial, when she first had the hearing loss, but the steroids did not help. They also tried to give her hyperbaric treatments with super saturation of oxygen without success. She said that acupuncture has helped with the vertigo. She has a cochlear implant and talked about the progress that was made, so she can now stream calls directly through the CI. Her devices help, but it's still frustrating that her devices do not have the same range as normal hearing. Also, is something that we didn't hear that much about, is that the cochlear implant can be irritating to the scalp at times. So she hopes that future technology is refining, and that more accommodations are made in society.

Larry Bauer, RN, MA ([05:22:44](#)):

Then we heard from James, a dad and physics professor who inherited hearing loss from his mother and his three kids have it as well. He talked about the challenges in high school needing hearing aids, but not wanting to wear them, because the stigma. He still struggles, even with hearing aids with regular conversation and speech. He said, it's trial and error to find the best hearing aid. He goes to the audiologist and tries new ones to see how they work. He says, "I find myself socially opting out more and more, and he would like to see more precise devices that filter sound better and improve speech intelligibility."

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(Completed 05/27/21)

Larry Bauer, RN, MA (05:23:22):

So we've heard consistently that devices have helped a lot, but are not still fully effective. There still is a great unmet medical need. People identified that restoring hearing would be a goal, but some people said even just improvement would be a big help. People would also like to have more help with tinnitus, and there continues to be a great unmet need in hearing loss community. So at this point, I'd like to turn the meeting back over to Barbara Kelley from the Hearing Loss Association of America, to close the day for us. So thank you.

Barbara Kelley (05:23:54):

Thank you, Larry. I really appreciate that recap. This has been a day of hearing personal insights to help understand hearing loss and its impact. Thank you to the FDA for permitting HLAA to hold this meeting and to your staff who tuned in today. I want to thank Will Lewellen, from the FDA, who guided us through this process. Thank you to Dr. Gavin Imperato, from the FDA, and to Dr. Frank Lin from the Johns Hopkins School of Public Health. Thank you to Dudley Digital Works, our media team today, our captioners, our sign language interpreter, and to James Valentine and Larry Bauer, and, of course, to the HLAA staff who worked very hard to plan this meeting.

Barbara Kelley (05:24:39):

Thank you to all our supporters and our partner organizations from around the world. Perhaps the biggest appreciation goes to you, people with hearing loss and those concerned about hearing health, who shared your experiences. Especially, our panelists and discussion starters. Also, to those of you who are called in or wrote in, giving your insights and your comments. This meeting could not achieve its goals, if it weren't for you.

Barbara Kelley (05:25:07):

We'll compile all the information in a Voice of the Patient report, which will be available on the HLAA website, along with the recording of today's meeting and a transcript of the full meeting. The web link to submit comments for the report is open for another 30 days. So please consider submitting additional comments, which will be added to the Voice of the Patient report. The video and the report along with a list of supporters and partner organizations, is publicly available to anyone once it's published. It will be posted on our website at hearingloss.org. There will also be a link from the FDA website.

Barbara Kelley (05:25:50):

Thank you to everyone for joining. You've helped document what it's like to live with hearing loss. We all hope for solutions to hearing loss and for better hearing health. This meeting today, and what everyone contributed, is a step to that future. The impact of this meeting will be felt for years to come. One final word, if you think you have a hearing loss, get your hearing checked and take action. Do something about it. Hearing health is critical to living a healthy vital life. Thank you, James, and for everyone who attended today,

PART 10 OF 10 ENDS [05:27:05]