



SoundBites Podcast Transcript

Episode: Barbara Kelley / Hearing Loss Association of America (HLAA)

Dave Fabry: Okay. Welcome to Starkey Sound Bites. I'm your host, Dave Fabry, Starkey's Chief Innovation Officer. Our guest today is the head of the nation's leading organization representing people with hearing loss, the Hearing Loss Association of America or HLAA. Starkey's been a proud partner and supporter of this very important organization for many years and we're delighted to have this time to chat with Executive Director Barbara Kelley, about the great things that HLAA is doing for the hearing loss community and how hearing healthcare providers can get involved. Barbara, welcome to Starkey Sound Bites.

Barbara Kelley: Thank you, Dave. It's a pleasure to be here.

Dave Fabry: Well, we're long overdue on getting together with you. And first things first, I think I've had the good fortune of being involved with HLAA since it was called almost an equally unpronounceable acronym, the Self-Help for Hard of Hearing. So, we went from SHHH to HLAA. Let's talk a little bit about the genesis of this organization, which I believe began right at the very beginning of my career, over 40 years ago now, right?

Barbara Kelley: Probably so, Dave. We were founded in 1979 by Rocky Stone, who retired early from the CIA, who operated in his career as a chief of station in Rome and he was in the middle east. The whole time, he wore a big visible body aid, but Rocky was really talented. He used the residual hearing that he had. He was an expert lip reader. He lip read in Farsi and Italian and English. And he started the organization, because when he retired, he realized that there were a lot of people like him who were between those two worlds, not totally deaf and not totally hearing but in between. And he found that there was nothing.

So, that was the inspiration to find the organization under the name of Self-Help for Hard of Hearing People. And in 1979, Self-Help was very much in style. That was the words of the day, but that philosophy is still true today that you give people all the good information they need about their hearing loss and they can make choices about what to do. So, we very much live that philosophy today, even though we're called the Hearing Loss Association of America.

Dave Fabry: Well, thank you for that background and perspective. I had the good fortune to meet Rocky early in my career when I was working at Walter Reed Army Medical Center and living in Washington, DC. Dr. Lucille Beck introduced me to him at the time they were in their first headquarters. And then just moving in, they had the grand opening. I want to say it was somewhere around '88 or '89 into the now, that's I think a couple offices ago, because there has been such growth in the organization, but what a remarkable human being he was. And I



believe it was in the '90s when he ultimately got a cochlear implant, if I'm not mistaken.

Barbara Kelley: He did. Rocky, by the time he retired, I think it was about 1996, he was also losing his vision because he's had macular degeneration. And I remember in the early days, I was hired in 1988. So, I do remember you, Dave, in the early days, and of course, Dr. Lucille Beck. I'm still in touch with her and she was a member of our board. But in the early days, Rocky was so open to change. He was open to anything, but he always said, "No, I'm not getting a cochlear implant." But that was so unlike Rocky.

Dave Fabry: It was.

Barbara Kelley: It really was, because I remember when he retired, his words to me were, "Barbara, keep saying yes to the future." And that was his attitude. So, very surprising, he would say that. But of course, when he started losing his vision and he retired and he had both hearing and vision loss and he depended so much on lip reading, he knew that it was time. He was a great proponent of cochlear implants and any technology that would help people.

Dave Fabry: Absolutely. Well, and another early leader within SHHH and HLAA was Mark Ross who also had a significant hearing loss and he was the editor of your magazine for many years. And one of the things that I always admired about Mark was, similar to Rocky, we talk about the stigma associated with hearing loss and the use of hearing aids, but that doesn't pertain to HLAA members in my mind. I think of the early days when I would speak at a conference and I would have seven homemade transmitters wirelessly or wired. Mark had a little antenna that he took off of a radio, and then he put the remote microphone on it. He would extend it out and just unabashedly saying, "I need this to hear better."

And it's really why I've been such a fan of HLAA for all of these years is because it truly is self-help oriented and advocacy oriented. Mark used to say that when you admit you have a hearing loss, you're admitting to the world that there's an issue. But the challenge is when you're using assistive technology, like those remote mics, you're directly involving other people in your "disability". But I love that the association and the advocacy for those with hearing loss says, "I will do whatever it takes," and talking about stemming from Rocky, "I will take whatever technology can provide me to help me communicate with other people and connect to each other." So that's really the history.

And then let's talk about under your leadership, HLAA has been growing by leaps and bounds. And I want to talk a bit about what some of your primary initiatives are now and your vision for the future. So, let's dive in a little bit on some of the initiatives for 2022 and beyond under your stewardship.



Barbara Kelley:

Dave, I love the way you captured that with technology, because our community or people who associate themselves with HLAA, whether it's at our Walk for Hearing or at a convention or they get our e-news or go to one of our local chapters, that's the attitude of people who want to stay in the hearing world with technology. We have a strategic plan and one of those pillars of our strategic plan is to reach more people. There's a perception, and often, perception is reality that our community is people who have severe to profound hearing loss.

And I think part of that is because I think people who have severe to profound hearing loss tend to need the most help. So, they come to our chapters where they get really good information and that really important peer-to-peer support, which you can only get in a chapter. I mean, you don't get that by really belonging to a national organization or the people who come to our conventions. So, we know that there are many more people who need help with their hearing, who need to take that first step, who need to think about their hearing loss in the world of hearing health. And you need to pay attention to hearing health very early on.

So, we are making some very calculated plays into reaching more people. And I think that's what we all want to do. We have that common goal. This is a big nut to crack and we can't do it just from HLAA. We can't do it just from the hearing aid industry or other organizations, audiological organizations. We all have to come together and find out how to work together to do what we need to do and reach more people.

Dave Fabry:

Absolutely. I can't emphasize that enough, and we spend so much time trying to in many cases in the past tear each other down, even though we're all united in our focus and our passion around those with hearing and hearing and balance disorders. And there's plenty of other things to fight out there, but to unify, I think, has really been the hallmark of what I've seen you do since you've been at the helm of HLAA. And I thank you for that, because I think it's so important that providers, manufacturers, patients, end users, consumers, whatever you want to call them these days, members of HLAA, that we unify and make sure that we're seeing the benefits of this technology while ensuring that there is no harm provided by that technology.

And I think also another area, having attended the conference earlier this year, accessibility, I think, equity is an important part of what I saw in the luncheon that I discussed. And I think it's really important to consider accessibility for all. And I think one of your initiatives with regards to looping and telecoils, we know that despite the wonderful advances that we've seen with Bluetooth and Bluetooth connectivity to smartphones, telecoil in many cases still represent an accessibility and equity issue that for those individuals who have their places of worship or adult classrooms, college campuses where they're already looped, it's a very effective means of communication.



I really enjoyed the forum where we had some discussions really looking at how we unify this wireless technology that is remarkable with both Bluetooth and loop and making room for everyone in the big tent, if you will, in the sake of communication.

Barbara Kelley: And yes, Dave, that's really important because it's about access. We look to the future, we hope to the future when Bluetooth is completely accessible to everyone, but yet until then, which it's not ubiquitous, people do depend on their telecoils. So, they need devices, hearing aids, cochlear implants with telecoils. And you're right in that hearing aid panel that we had at the convention, there were a few people who stood up and very passionately talking to hearing aid manufacturers that we depend on our telecoils. And I think the future looks bright for accessibility because of the explosion of technology.

And because Bluetooth will most likely be for everybody, people who have hearing, people who need hearing aids and cochlear implants, we know that when it's ubiquitous and it's for everybody, that's when we're all on that even plane. We have equal access. And I look forward to the day when I can have something on my smartphone and something in my ear, where I can have sound clarity, because everybody wants good audio clarity, no matter what we're doing.

We're in an airport and we can't hear the announcements over the loudspeaker or we're at a concert and we really want that high fidelity. So, I think when that type of access to sound quality is for everyone, that's when people with hearing loss are going to be on the equal footing. But you're right, we do have other technologies. The telecoil is still really important to people.

Dave Fabry: Yeah. Like you said, there is going to be a point in time where someone will be able to walk into a movie theater or a place of worship and be hit immediately with the opportunity to pair with whatever public address or sound system is available. We're not there yet. And so, in that transition, we really need to remember, I get very excited about the technology, but when we have solutions that are already in place and highly effective, it was great to participate on that panel discussion and hear from members. That's what keeps us honest is that engagement between manufacturers, industry, and the people that are wearing our technology. So, it was great discussion and I really appreciated the candid, and if you will, radical candor that was shared between the parties at that panel.

Barbara Kelley: That's so interesting. Thank you, first of all, for coming to the HCAA convention this year. It's our first convention in person for two years since COVID. And we hear that across the board, Dave, from manufacturers and from industry that you can't replace the user experience and the candid experience. I just was talking to somebody last week who attended the convention for the first time and he's a hearing aid wearer. He said, "Barbara, I've never met so many people



in one place who really are in the know about hearing technology and advocates. They want access and they understand what's going on, because I think the general public out there, hearing health and what to do is still very muddy."

It's tough. We make that analogy. You put on a pair of glasses, it corrects your vision, but we know that you put in hearing aids and it takes work. It's a positive step, but very intelligent, educated people just don't know what to do when it comes to taking care of their hearing. It's just not muddy. So, you get to an HLAA convention and you meet a lot of people who know a lot of things about their own hearing loss or want to learn.

Dave Fabry: Well, I couldn't agree more and echo that and also will say that it was indeed a pleasure to attend in person that conference in Tampa. And also, that it was Tampa, right?

Barbara Kelley: Yes, it was Tampa.

Dave Fabry: I'm losing track. Travel is starting up again, but it was so great to be there. Starkey was a proud presenting sponsor at that convention and we also sponsored the Walk for Hearing. It aligns so well with us, because with our products now, the latest generation Evolv, incorporating sensors directly in the hearing aids that can track physical activity, that's really done with a purpose. That's because we know that there is a strong comorbidity between hearing loss and cardiovascular disease on overall health and wellness. And so, we know there are links between obesity, diabetes, high blood pressure, all of which can be helped by people being more active if they have hearing loss.

And so, that Walk for Hearing is a perfect alignment between our movement on turning hearing aids from single purpose devices into multipurpose multifunction ones that relate to health and wellness. But talk a little bit about why it is that HLAA decided to use the Walk for Hearing and how successful has that been.

Barbara Kelley: Well, the Walk for Hearing is more than 15 years old. We started it over 15 years ago, and personally, it is one of my favorite events. We're in 20 cities across the country at different times in the spring and fall. And the Walk for Hearing is where we really see the diversity of people who come out that truly represent that community where we are. We see different ages of people. We see parents with children who have hearing loss. We see representation in cultural diversity. It's a huge day of not only fun, but awareness for that community and where we are. The cities look now to us to be there and it's often people who don't know anything about hearing loss or hearing health. They become aware of the Walk for Hearing.



Sometimes people will bring their family members. We try to have hearing screening vans at the Walk for Hearing. So, if I bring my husband or my brother, oh, there's hearing screening right there. So, that becomes an awareness campaign right there. But the Walk for Hearings, they've been just great outreach and awareness vehicles for us that brings people together in a really fun environment. And everybody likes to join in a walk. I have to tell you, some people don't even walk. They just come and they have fun and they hang out. We have our partners there and they'll visit the different tables.

They'll eat the snacks and they won't actually take the walk, but many people take the walk. I just love seeing the kids with hearing loss. Some of these children for the first time ever, they meet another child who wears a device. That just opens up. It's really a big thing for a child that there's other people like me. And then the parents, of course, get to share with each other and lifelong friendships are made.

Dave Fabry: Well, I think it is such an important part of that initiative and the fact that you go to... You said 24 cities now?

Barbara Kelley: Twenty cities.

Dave Fabry: Twenty cities, okay.

Barbara Kelley: Twenty cities.

Dave Fabry: I think also, the accessibility of going into those communities, raising awareness for the importance of screening hearing, why it's important that they do something about their hearing loss if they have one, being able to bond with others, I think are all really important ways that you can provide advocacy and accessibility. And I think the other point that you made is such a good one on diversity and inclusion too in those different communities. One of the things we know is that hearing aids in many cases are still very expensive. And in some cases, people have difficulty affording them and providing information as to what sources might be available for getting hearing aids or alternate ways that they can do so.

And then that importance, as you said, for children who are fitted with hearing aids, being able to bond with other kids and people of different ethnic backgrounds. I mean, there's the saying, you can't be what you can't see. And if you don't realize and recognize that we have to represent the overall society in terms of the technologies and the services that are available, it's such an important grassroots initiative that you're doing across the country. Is HLAA predominantly a US-based organization, or do you have other chapters outside of the US?



Barbara Kelley: Well, we're predominantly US based. We're a member of the World Hearing Forum. We do have global initiatives, but we're really US based with our chapters across the country and our Walk for Hearing. And you hit the nail on the head, Dave. I like to say that hearing loss is an equal opportunity employer. It doesn't matter what your cultural background is, what age you are. I mean, all of us, I'm realizing now, will at some point have a hearing loss. I had the opportunity to have you do my audiogram when I had a visit to Starkey. To my great surprise, it showed the high frequency hearing loss. You would think that I would know what you do with that information.

And I said to our board chair, Kevin Frank, I said, "Kevin, I have this high frequency hearing loss. What should I do?" And he goes, "Barbara, you know what to do. You know when it starts becoming a problem what you do." I said, "Of course, I know what to do."

Taking care of your hearing health is still a really fuzzy situation and I think the Walk for Hearing is also a fundraiser. We can't dismiss that part of it, but what's really great is we have alliances in these local communities across the country and they raise money for programs that stay in the community. So, that even has the reach where the national organization itself can't get into those communities. So, it's a really important event and we love the Walk for Hearing.

Dave Fabry: Excellent. So, before we go on, listening on Starkey Sound Bites, we have professionals and we also have end users, people with hearing loss who might be looking for information. And so, could you provide the website location for the national organization for Hearing Loss Association? And then also, let's say, I want to see if there's a local chapter, how would I find out if there's a local chapter? And if so, how do I join in? Because you're making a strong case that there are benefits both of being a national member and being involved in that national convention and some of the other educational events that we'll talk about, but then how about at the local level? How do I find out locally and nationally how to join?

Barbara Kelley: Sure. That's a great question, Dave. Well, go to www.hearingloss.org, and you will get all the information you need. And if you want to find out about a local chapter, there is a dropdown menu there. It's Find a Local Chapter and that's where all our chapters are listed across the country. We also have a tab for the Walk for Hearing, if you want to get involved in the Walk for Hearing. And if you're a person who might want to start a chapter or not even think that far down the road, but maybe you want to get a group of people together that you know, who want to share information and support each other, you can loosely form as an HLAA group. We'll give you a little bit of branding. We'll put your name on our website, and then you never know, that could grow.

And what we found out during the pandemic as many people found out that we have this new technology tool of online meetings. So, that was the other thing



that we found out during the pandemic is that hearing loss is isolating enough and then you add that extra layer of isolation of not being able to see your friends and family. So, this online technology, we're on Zoom today, was so helpful because there's captions. We found out that people in the workplace were having meetings on these online platforms.

And all of a sudden, because of captions and because of maybe sound quality with their computers, they were all of a sudden on an equal playing field. They were not sitting around a big conference table in a meeting room not being able to hear. And of course, we know there's assistive technologies that could help with that, but a lot of people don't know about it.

Dave Fabry: Absolutely. I think a lot of people still are unaware that on PowerPoint and on Zoom and a lot of these web-based platforms, you can go and turn on captions.

And I make it a point in my presentations to turn on captioning for use by everyone, especially those with hearing loss, but it is a great leveler to realize now in addition to the wonderful real-time captioning that we've had at HLAA meetings for a long time, it's becoming more and more commonplace to have artificial intelligence enhanced captioning for use on a conference call that you might have with your grandparents or your kids and to take advantage of that to ease the communication between parties when we don't have the benefit of three dimensions to look at. We're looking at screens like we are today, and it's something that people need to be aware of, because if you don't know it, you can't use it.

Barbara Kelley: That's true. Dave, I bet when you go to a party and they find out what you do, I bet you're the most popular person in the room, because I have to tell you. I went to a party Saturday night and a woman asked me, "What do you do?" I say, "I work for a national organization for people with hearing loss." I give them the broad, rather than getting into the nitty gritty. All of a sudden, "you have to talk to my husband." That probably happens to you.

Dave Fabry: Yeah, I'm rarely the most popular person at a party, but increasing as I get older and my friends do too, many of them start to want to talk about their hearing loss.

Barbara Kelley: Exactly. And so, that's when I become very popular, because all of a sudden, I'm talking to this very intelligent, retired air force engineer, retired officer. He just doesn't know what to do about his hearing loss and he thinks that he's the only one in the world who has a problem with hearing speech and noise. And he's telling me this, like he's the only one. And then he told me he was on a Teams meeting that morning and he said, "I was so lost. I couldn't understand anything."



And I said, "Do you know that if you go up to those three little dots at the top, you can turn on caption?" Well, it's like I just opened up a world to him. Why don't people know about these things? And that's where we are trying not only to advocate, we work with the FCC. We're on the Disability Advisory Panel. We work with regulatory, public policy, legislation to make sure that these platforms are accessible for people with hearing loss, but then we have to get people to know about them.

Dave Fabry:

Right. We have to ensure that accessibility for those with hearing loss is available, but then we have to make it aware for the general population that these technologies and abilities exist. And so, I think that's where HLAA has been so instrumental.

We talked about the perception that HLAA is for those with more significant losses. I can tell you that having just even been at the convention this time and in past years, that's not the case, that even if you have somewhat considered a mild or moderate degree of hearing loss, there's so much that people can learn by participating at the local level or the national level and the conferences or even the educational offerings that you have.

Dave Fabry:

I want to talk a little bit about you hosted a conference this year, not only looking at what to do with regards to technology that exists today in the form of hearing aids or cochlear implants, but really with a future view towards developing and emerging technologies. Right now, the vast majority of hearing losses are not treatable by any medical or surgical treatment. But earlier this year, you had a conference dedicated to emerging technologies for treatment. How successful was that?

Barbara Kelley:

We did. That was the Patient-Focused Drug Development Conference that we hosted and this was primarily the audience for the FDA. There were three divisions of the FDA who tuned in, the devices division that creates and approves technology, and the pharmaceutical division, and then the soft tissues division, which deals with genetics. With permission from the FDA, we were able to put on this day-long conference and really what it highlighted was the impact of hearing loss on people's daily life. And it was really eye-opening.

I have to say that it's probably the only place where there's the most qualitative data about living with hearing loss and there is a Voice of the Patient Report that was a product of that meeting. That's available on our website at hearingloss.org, as well as the recording of the day. But we had panelists from different backgrounds, different degrees of hearing loss, different causes of hearing loss

And what I think is really exciting is the FDA said to us, "You might want to, in planning this meeting, reach out to some partner organizations to see if they



would like to not really be part of it, but just put their name to it, to show that they're there, they support it."

So, we reached out to people and we had 54 partner organizations. They not only were organizations, but some academia, some industry. Starkey was part of that. And the FDA said to us, "HLAA got more partner organizations in the history of these PFDD meetings." I mean, generally, they're thinking about getting three or four partner organizations, but there are so many people interested in hearing health. So, we were very pleased to bring on all these partner organizations for that meeting.

Dave Fabry:

Yeah. That's why I wanted to be sure to talk about that a little bit anyway, just because of how impressive it was that you were able to get so many people to come together for this discussion. Throughout my career, I mean, early on, I had to really almost arm wrestle people to get them to wear hearing aids. And I'm thinking we're really seeing attitudes change about what it means to have healthy hearing. And I think the pandemic taught us all, even those of us with even mild amounts of hearing loss, how important it is to be connected to each other. Primarily, with all respect to those who use manual communication, we're connecting to each other through our ears and through hearing. And I think you're right.

I mean the aging baby boomer were egocentric, but I think there are many of us that are getting and experiencing hearing loss, even if we didn't have it earlier in life. And so, it is raising the awareness and the importance, even attracting the interest of the last several administrations in trying to figure out how to address through Medicare or through over-the-counter hearing aids ways to increase adoption rates by those who have hearing loss. You and I both know that only a third of the people with hearing loss in the US actually do something about it in the form of hearing aids or cochlear implants.

And so, I think we're both aligned in saying that any way that we can raise awareness for and adoption by those with hearing loss to use some form of technology is a good thing. I don't want to put words in your mouth, but I think we're aligned on that.

Barbara Kelley:

We are definitely aligned. Let's drive people to hearing care. And I like to think, because I'm a baby boomer myself, is that I like to think that we're a generation who wants to do anything we can to stay with it and fit. I mean, we exercise. We take vitamins. We keep our mind tuned. Well, taking care of your hearing health is part of that, because if you don't and you're missing, conversation and hearing is part of the human experience. It's how we relate. It's how we be immersed in life. And if you're taken out of that and you are not looking as sharp as you could be because you're not hearing, that's really not part of what I think the baby boomer generation is all about. I mean, we want to do anything we can to stay active and involved.



I like to use the example on my husband who says to me, he goes, "I don't need a hearing aid all the time." That's a matter of opinion. Maybe he does. Maybe he doesn't. But he likes to say that "I just need a little hearing enhancement from time to time," situational. That's how he's reconciled it in his mind, in his lifestyle, and what he wants to do about his hearing health. And I think that's the way we have to start talking about it is not always, "Go get hearing aids and this is what you need," but meet people where they are.

And I can tell you that he will eventually end up with those hearing aids that are pretty sophisticated that he's wearing all the time, but this is the way he's decided to take that first step. And no matter what I say, no matter what organization I work for, no matter how many conventions he's gone to, this is how he's settled it in his mind.

Dave Fabry: You took the words out of my mouth. We have to meet people where they are at that moment in time. And one of my favorite taglines of all time was the Self-Help for Hard of Hearing one where your hearing loss is more conspicuous than your hearing aids. And when it becomes an issue where he starts to recognize that he needs help all the time, he'll get there, but we all have to go at our own pace. That phrase always goes over and over in my mind of your hearing loss being more conspicuous than your hearing aids. I long for the time and I think we're really close. We're seeing changes where people say, "I don't care that people see that I'm wearing if I'm getting the help that I need to be as fully engaged as possible."

Barbara Kelley: Exactly. Dave, that was a Mark Ross quote.

Dave Fabry: I know it was. Yeah.

Barbara Kelley: Yeah.

Dave Fabry: I love that tagline. You should bring it back.

Barbara Kelley: Let's bring it back. Right.

Dave Fabry: It's so relevant to today too. I think, especially with that baby boomer mantra of wanting to live our best life at every stage of life, that I think it's time to resurrect that one in homage to Mark.

Barbara Kelley: I'm going to get right on that one when we get off-

Dave Fabry: All right. Thank you, Barbara.

Barbara Kelley: ... this podcast.



Dave Fabry: Well, we're out of time. We have started a tradition of asking participants a little bit about their favorite sounds. This is Sound Bites. So, if you were to reflect on what some of your favorite sounds are and if you want to make it more of a song or musical artist or nature sounds, can you think of those sounds that are your favorite, a couple of them?

Barbara Kelley: Yes. Yes. My favorite sounds and you didn't prep me for this and the answer is so easy for me, is our son just graduated from college this year. He and all his friends are no longer filling this house with their loud, raucous roars, their laughter from the basement in their college years. They would get together and they would play poker when they would come home on college break and we would hear it clear up in the bedroom. That's what I love is the kids, the young men who pass through this house. My house is really quiet right now. Those are my favorite sounds.

Dave Fabry: The sound of silence and that life that they bring. Oh, that's great. That's a great one and thank you for sharing that with me and our audience.

Well, I can't thank you enough, Barbara, for spending this time, talking a little bit about the history of HLAA and where you're going now with the organization. Congratulations on this tremendous growth. Starkey is just so pleased to collaborate with you on your efforts and to be a strong partner to HLAA and we look forward to many future endeavors together.

Barbara Kelley: Well, thank you, Dave. We appreciate partnering with Starkey. We have a lot of work to do, don't we? But we're going to do it.

Dave Fabry: Yes, we do. I count my blessings to think about the fact that this is my 40th year in the discipline, and I can honestly say there are challenging days for sure. But every morning, I wake up with just as strong of passion or energy as I did 40 years ago, because there is so much opportunity. There's always challenges, but there's a lot of opportunity out there. I'm delighted to be on this journey with you.

Barbara Kelley: Thank you. I totally agree.

Dave Fabry: Great. Well, to our listeners, we thank you for listening to this episode of Starkey Sound Bites. And if you enjoyed this conversation, please rate and review us on your preferred podcast platform. You can also follow us or hit subscribe to be sure that you don't miss a single episode, and we'll look forward to hearing you and seeing you next time. And thanks again, Barbara.

Barbara Kelley: Thank you, Dave. Thank you, everyone.