

A Sense of Belonging

BY LYNN JOHNSON

I have belonged to several Facebook support groups for awhile, including the Vestibular Disorders Association. My hearing loss is due to an autoimmune disease called Cogan’s syndrome, which is an inflammation that affects my balance and hearing, as well as my vision. I have bilateral vestibular hypofunction, which is the scientific name for severe imbalance, oscillopsia or eye jumping, bilateral tinnitus and bilateral profound deafness.

Feeling Down About My Deafness

In these support groups, I occasionally found someone else who suffered from hearing loss. Of all my symptoms, my hearing loss is the most challenging, so I found myself focusing on and feeling depressed about hearing loss more than anything else. I found some level of connection with the Vestibular Disorders Association Facebook page.

I figured there must be something for hearing loss, too, so I went to the sensorineural hearing loss support group page on Facebook. It was there, in response to posts I had shared about my symptoms and what I was going through, that someone said to me, you should reach out to a local HLAA Chapter. I didn’t pay attention at the time; I was distracted because some of my symptoms, including my hearing, were growing worse.

Losing more hearing affected how I interacted with my family and friends, as well as everything else I did.

I was so depressed, and I expressed my feelings to someone on that site, and they again replied, “You need to join HLAA.” I was in one of my cheerful moments, and I decided to explore the HLAA website and find out more. I realized I needed to connect with people who understand what I’m going through because I feel so alone. I saw the notice about the HLAA Virtual Meeting with Barbara Kelley via Zoom (whatever that was!), and I decided to see what it was about.

Clicking With HLAA

I immediately identified with the content in the HLAA Virtual Meeting. I felt the connection. It discussed the very issues that I was facing, and I could feel that the people there felt what I was feeling.

At that point, HLAA connected me with the HLAA All Generations Chapter in Pennsylvania and Ronnie Adler, and she invited me to attend the virtual HLAA Pennsylvania Walk4Hearing and game night for the chapter.

I decided to invite my twin sister, Dr. Leslie Childs, to game night, because she can tell when I’m disengaged; she can hear it. She immediately texts me and explains what I am missing or not understanding. Having her participate with the group was a plus. I love interacting with the chapter; I don’t feel judged by anyone, even if I misinterpret what is said or have not heard or understood a question correctly. I am not dismissed or picked on, as is sometimes the case when I am with other people. No one does that there. And I felt really good about that. When you experience hearing loss, you go through a grieving process, and you’re very vulnerable; your self-image can be crushed. I am not as confident as I once was, and I had fun with this group because I didn’t feel like I was being judged.



From Feeling Bummed to Having Fun

I love Ronnie Adler and the Walk staff. Ronnie is a fun, outgoing person. She and her team had so much energy and passion, and they showed me that I didn’t have to remain depressed; I could still be passionate, confident and have fun, too. I really connected with Ronnie, and I remember looking at the Walk and saying, “These people really know how to live with hearing loss.” I felt the joy they had. And that made me connect with her. I felt that I could be a part of this group. I can see

they like having fun, and I needed to see that. All of these people share my hearing loss. I was in a bad place of grieving the old me, thinking it was all over, but when I saw them, I realized that I'm still the same person with the same gifts and energy. I just have to find new ways to express them.

Vestibular issues and hearing loss can be very isolating and depressing. There is loss and suffering involved, and you can lose a lot—financially, emotionally and professionally. For me, it has felt like a spiritual journey, and God has used HLAA to get me to the place where I am today. When I first attended that HLAA Virtual Meeting, I was really in a bad place emotionally, because I was focusing on my hearing loss. But today, after befriending these people, I have peace about my hearing loss. My attitude now is: "I'm still the same person with the same gifts and the same energy!"

Game night restored my sense of normal fun, so I have to thank the people of HLAA because just having that means a lot. You can still have fun in the midst of everything that you're going through. There is still such joy to be found in life—like playing games.

Trading Grief for Gratitude

As I move forward, my hearing is going up and down. When I was evaluated for a cochlear implant, my medical

team decided that I hear too well with hearing aids. I improved physically, spiritually and mentally when I let go of trying to hold on to whatever hearing I have left. It's hard to express what I felt, but I said to myself, "So what if you're going to be deaf? You're definitely going to be okay, because life still goes on, and my HLAA friends have proven that you can still live, even if you can't hear."

I just want to encourage you. I want to remind you that your work is not in vain because you're touching people like me. And people are watching you, and they appreciate your efforts, and so do I. You never know who might take a quick glimpse at what you're doing. And that brief observation may help them find the power to move on, get out of that depression and become proactive about their hearing loss. You gave me the opportunity to express myself, and that means a lot. Thank you. **HL**



Lynn Johnson is from Secane, Pennsylvania. You can listen to Lynn speak at the HLAA Virtual Meeting on "Living and Loving With Hearing Loss" at YouTube.com/watch?v=HQ2xpEoX2O8



HLAA

CHAPTERS & STATE ORGANIZATIONS

Join a Chapter *Learn that you're not alone in your hearing journey!*

Find an HLAA Chapter near you by visiting hearingloss.org/chapters-state-orgs/find-a-chapter/.

For more information, including how to start a chapter, contact Carla Beyer-Smolin, HLAA chapter and membership coordinator, at cbeyer-smolin@hearingloss.org.

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