

“I raise up my voice—not so I can shout, but so that those without a voice can be heard.”

—Malala Yousafzai (1997–), Pakistani activist for female education and the youngest Nobel Laureate

Advocacy Matters: Be the Change

BY MELISSA TUMBLIN

Hearing loss can be a different journey for each one of us. It can be the only thing we have known since birth, or it can show up when we least expect it, changing our lives forever. While some of us choose to embrace hearing loss, others continue searching for options to try to restore their hearing. Either way, what matters most is that you find what works best for you. But what happens when you find what works best for you and then cannot get it?

We often forget that people assume things are just fine unless someone speaks up about it, but if no one speaks up, things will never change. This is why it is so important to advocate for the things you believe in. In fact, advocating not only provides the opportunity for individuals to enjoy a better quality of life but also improves standards of care and life for entire communities.



Melissa Tumblin and Ally are devoted advocates.

We Felt So Alone

In 2009, my daughter, Ally, was born without her right ear and also without an ear canal. This condition is known as microtia and aural atresia. In the beginning, our family felt very alone and could not find the answers we were looking for. As a mother, I wondered if I had done something during my pregnancy that may have caused Ally’s ear to be missing, even though I had a healthy pregnancy. My family felt lost from being caught up in all of the worries and concerns we had for Ally, and we had no one who could explain to us, step by step, what we needed to do. There was no community we could join that was comprised of children and adults just like my daughter, and we didn’t have a good understanding of Ally’s hearing loss. The medical professionals we consulted at Ally’s newborn hearing screening remarked, “She has one good ear and that’s good enough.”

Our Baha Breakthrough

When Ally was nearly 10 months old, our family realized she wasn’t hearing very well. She seemed to be a quiet baby and one day when I dropped a pan on the floor, she wasn’t startled by the loud noise. After wondering if she was struggling to hear, I read about a hearing device online that we should have been told about: a bone conduction implantable hearing device (Baha). Within a couple of weeks, we were able to obtain a loaner Baha from our audiologist. I will always remember this day, because when our audiologist switched the Baha on and whispered Ally’s name behind her ear, she whipped her head around, smiling as her face lit up! We both had tears of joy in our eyes, seeing how she responded to sound on that side of her head and seeing her facial expressions. It was truly a seeing-is-believing moment!

Even Ally’s early intervention therapists said it was as if someone flipped on a switch and she had become re-engaged with her environment. When it came time to obtain a Baha for Ally, our insurance provider didn’t cover this type of hearing device and denied our claim. We couldn’t believe it. We not only knew our daughter was missing her ear and had no ear canal, resulting in a diagnosis as moderate to severe hearing loss but also faced a barrier to getting her the very device that would help her. Even Ally’s hearing test showed how her hearing loss was brought right back up within normal hearing range when aided with a bone conduction implantable hearing device. I couldn’t help but ask myself, “Why would I not want my daughter to hear better

“I alone cannot change the world, but I can cast a stone across the waters to create many ripples.”

—Mother Teresa (1910–1997), Albanian-Indian Roman Catholic nun and missionary

with this hearing device? And why will our insurance not pay for it?”

Taking Matters Into Our Own Hands

Fast forward a decade later: after founding the Ear Community Organization and watching family after family be denied private insurance coverage for these hearing devices, we began advocating as an organization in 2019. From participating in Advocacy Day on Capitol Hill to meeting with representatives in person, we began advocating for osseointegrated hearing devices, which are surgically implanted in the bone, to be covered by private insurers.

However, it wasn't until Ally wrote a letter during Better Hearing and Speech Month that caught the attention of Congressman Joe Neguse of Colorado. As part of a homework assignment to help give back to the community, Ally decided to write to a lawmaker about a cause she cared about. She said, “Mom! We should write about my BAHA!” And, so we did! In her letter to Congressman Neguse, she asked him to help her advocate to hear better because other kids just like her can be helped by this device but insurance doesn't always cover the expense.

Congressman Neguse responded to Ally with a letter in which he said that he would continue to work on ways to help advocate alongside her. In December of 2019, Ally's Act became a reality, ensuring that private insurers would cover osseointegrated hearing devices, including Bahas and cochlear implants, for children and adults from birth to age 64. This January, Ally's Act was the first bill to be reintroduced in Congressman Neguse's office. Ally's Act, H.R. 477 and S. 41, are bicameral, bipartisan, national level bills co-sponsored by Rep. David McKinley and Rep. Mike Thompson, both of whom are co-chairs of the Congressional Hearing Health Caucus.

You Can Help, Too!

Anyone can write a letter and speak up just like Ally did! If something matters to you, advocate for it. If Ally's Act becomes law, hundreds of thousands of children and adults would have access to life-changing treatment, enabling them to participate in the workplace, school and community of their choice and enjoy a high quality of life. For more information on how you can help support Ally's Act, please visit earcommunity.org.

Since 2012, the Ear Community Organization has donated more than 135 Bahas to those whose claims have been denied by their private insurance providers. The organization has championed genetic research, established National Microtia Awareness Day and created a community for individuals living with microtia and atresia that was much needed. If you want to see the change, you've got to be the change: advocacy matters! **HL**

Melissa Tumblin is the founder and executive director of the Ear Community Organization and the Microtia and Atresia Support Group on Facebook. Melissa sits on many boards, councils and committees, including the National Institutes for Dental and Craniofacial Research, the Friends of the Congressional Hearing Health Caucus, and the Advisory Board for the CARE Research Project at Seattle Children's Hospital. She is also an advisory board member for a biotherapeutics company working on 3D printed stem cell-regenerated ears, and she has made accredited presentations for AudiologyOnline, Continued.edu, the Educational Audiology Association and at Early Hearing Detection and Intervention meetings. She has also presented at many hearing device manufacturer meetings, microtia and atresia surgical conferences and at the FDA. She launched the Microtia and Atresia Clinic at Vanderbilt University Medical Center and is a co-investigator on a whole genome sequencing genetic research grant with Harvard, Vanderbilt and the MIT Broad Institute. She established National Microtia Awareness Day and is the recipient of the Family Leadership Award for EHDI Excellence and the Oticon Medical Advocacy Award.

Alyssa “Ally” Tumblin is an advocate and poster child for the microtia and aural atresia community and is the reason why the Ear Community Organization was founded. Because of Ally's story and her advocacy, she has helped pave the way for many other children and adults with microtia and atresia, as well as their families, for the past decade. She is also an advocate for hearing device insurance legislation and has been honored by Ally's Act, legislation named for her. Ally is currently 11 1/2 years old, and she is the happiest little girl her parents know. The person she looks up to most in life is her big sister, Hailey, who is always there for her.