

Walk4Hearing: All in the Family

By Ronnie Adler and Ann Rancourt

The HLA Walk4Hearing rallies people together throughout the country for a common goal: to increase awareness, raise funds, and provide or find support with others who are affected by hearing loss. Something else common to many Walks is that they are a family affair. Parents, children, brothers, sisters, aunts, uncles, cousins—even grandparents—come out to walk in support of someone in their family with a hearing loss.

However, hearing loss is not always isolated to an individual or single generation, it can be inherited. Some find it just within their immediate family—a parent and at least one child who has hearing loss. But in other cases hearing loss can span several generations. We asked five families with multi-generational hearing loss to share their stories and to find out why they take part in the Walk4Hearing.

The Davis Family: Twists and Turns and Bumps in the Road

Our stories are frequently similar yet always unique. Our paths impeded by similar bumps in the road. We share similar worries as well as hopes and dreams.

Our family of six is no different. Our second child, Caroline, was diagnosed with hearing loss as she turned three. When our twins Clark and Stuart were born, they passed the newborn hearing screening. Yet we noticed that Clark was not responding to voices and sounds as much as his

brother. After additional testing, Clark was also diagnosed with a hearing loss. He received his first set of hearing aids when he was eight months old.

In less than three months, two of our four children were diagnosed with hearing loss. Then three years ago as my husband was driving his car, he heard a strange-pitched noise and a “pop.” My husband Evan now has a bone conduction system implant.

Evan and I were determined from the start that we would support all of our children in chasing every dream. Even when Caroline wished to pursue singing and drama, we never wavered in our support. Countless productions later, including a lead in a musical, we don’t think twice about what is possible. Even playing ice hockey had its challenges. But Caroline is now playing for the women’s club team at the Rochester Institute of Technology and Clark made varsity as a freshman in high school.

Those twists and turns in the road have led to unexpected and exciting destinations. I took a job with CaptionCall, advocating for those with hearing loss and bringing captioned phone services to the Deaf and those with hearing loss. It was through my work that I learned about the HLA Walk4Hearing. Our family



The Davis family, left to right: Stuart (16), Wendy, Evan, Clark (16), and Caroline (19).

has served on the planning board for the Pennsylvania Walk4Hearing and walked as the Davis 6 Team for the last three years. For Caroline and Clark, participating in the planning of the Walk has been a great experience and their input representing the views of our youth has been invaluable. We are there as a family, surrounded by friends we have met on our journey, friends with whom we share more than just the bumps in the road.

The Davis family lives in Malvern, Pennsylvania and participates in the Pennsylvania Walk4Hearing.

The Lieberman Family: Hearing Loss Can’t Take Away from Perfection

January 13, 2010, was a day that changed my life forever. My wife gave birth to our first child, Lily. With her light blue eyes, cute little nose, and blonde fuzzy hair, Lily was absolutely PERFECT!



Scott Lieberman with daughter Lily (6)

It wasn't until Lily had a newborn hearing screening did that nostalgic aura start to wear off. The doctor gave us the news that Lily failed her screening.

The next few weeks proved to be emotionally difficult. One of our first responsibilities was to take Lily for an Auditory Brainstem Response test to determine the severity of her hearing loss. We learned Lily had a severe hearing loss in both ears. We met with many audiologists and therapists and they all concluded the same thing: Lily should be fitted with hearing aids.

At six weeks old, Lily's grandfather Stephan Weitz of the Hearing Aid Center of Forest Hills (New York) fitted her with her first set of hearing aids. During the appointment, my father-in-law turned to me and said, "I don't understand why everybody is upset, Lily is just like us and we didn't turn out so bad." Lily is just like us in more ways than one. Stephan, myself, Lily's uncle and grandmother all have a hearing loss too.

I realized that hearing loss is not going to define my daughter. She needs to grow up empowered, chasing her dreams. She needs to know she can achieve anything she wants, and

she will have the support of her family, friends, and professional organizations.

We found tremendous comfort, resources and support through HLAA. We walk in the New York City Walk4Hearing in honor of Team Cleary, Lily's first school. It motivates my family, encourages us to advocate about hearing loss, and gives us a chance to give back to those who have helped our family.

Approximately 30 family members join us at this momentous event. Some past participants include family, friends, aunts, uncles, cousins, parents, grandparents, and even great-grandparents. Our team of walkers continues to grow every year. We even had some cousins from Italy attend the Walk. One thing that never changes is the sense of pride I feel as we gather to support Lily. It is a very rewarding experience that I look forward to every year.

Humility goes a long way. I needed to change my own reaction to the disability I have. I do not want my daughter being labeled or growing up with the stigma associated with hearing loss. I pledged to make a difference for

hearing loss; I want to be a role model for my daughter, friends, and family. Next time there is a bump in the road or something to "feel sorry for," embrace the situation and see what you can do to make a difference. After all, my Lily still is PERFECT!

The Lieberman family lives in Smithtown, New York and participates in the New York City Walk4Hearing.

The Van Rooy Family: Define "Normal"

"I was born deaf. I was raised in a hearing world and in a deaf world at the same time. I can't say that I like one better than the other."

—Sean Berdy, actor

When I read this quote, it reminds me that hearing loss is actually quite normal in my life. In fact, it has been commonplace in my family for at least six generations. Growing up, I remember my grandma was always yelling because my grandfather couldn't hear a thing, and he never wanted to wear a hearing aid. We all just knew that if we wanted to talk to PopPop, we had to shout. It was many years later before he reluctantly got his first pair of hearing aids. We probably still shouted.

His daughter, my mom, got her first hearing device when she was four years old back in 1947. It was called

a vacuum tube aid. It was heavy and clumsy, but she loved it because she could hear better. It was years later before she got a behind-the-ear (BTE) aid.

As for me, when I was a toddler, my parents were not sure if I had hearing loss. Then one day, I was standing in the doorway and my brother came up behind me and said, "Boo!" When I said, "Where is Ricky?" that's when they

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The Van Rooy family, left to right: Michael (19), Colleen, Jessica (16), and Jamie (15)

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knew for sure. I didn't get fitted for BTEs until I was four years old. My mom tells me that when I wore them for the first time my eyes became huge. I giggled, I smiled, I clapped my hands, and I talked and talked and made noises.

My sister has hearing loss too, as do two of her children. Three of my four children have hearing loss. The younger generation—my kids and their cousins—have been wearing hearing aids nearly all their lives. This is why we say that hearing loss is normal in our family. It's what we are accustomed to; it's what we live with every single day.

I love how many people come to the annual Walk4Hearing events and make it a family experience. We create awareness through the Walk. No matter what your age or where you are from, it's nice to be around people who understand and show support so we don't feel alone. Most everyone at the Walk4Hearing is there because they either have hearing loss or know someone with hearing loss. Walk day is something our family looks forward to every year. It reminds us that we are not alone and that together we are walking because it's about families like ours!

The Van Rooy family lives in Appleton, Wisconsin and participates in the Milwaukee Walk4Hearing.

The Wathen Family: Just Keep Pressing On

Upon hearing the news that I would be a father, the excitement and joy I felt was somewhat overshadowed by the fact that my child could have a hearing loss. As a child growing up with hearing loss, I knew what it was like to be part of a world that only a few could relate. As the son of parents with hearing loss, I knew I would be alright. As a father of a child

that could possibly have a hearing loss, I was scared.

My older son, Tristan, was indeed born with a mild-to-moderate hearing loss. With my second son Lucas, I pretty much accepted the fact that he would have a hearing loss right from the start. Sure enough, his results were pretty much the same as his brother's.

I played sports and was involved in a few clubs within my school and temple when I was young. Being active helped me gain friends and definitely helped me with my confidence. My parents, who also have a hearing loss, were able to share their experiences with me and were able to understand my struggles and frustrations. My brother Daniel has a hearing loss as well. We could relate and understand each other through our hearing loss struggles and experiences, both good and bad. My family helped me press on.

My boys are now 14 and nine. They are active in their schools and community. There have been times when they've struggled due to their hearing loss but have managed to learn to become advocates for themselves. Tristan is at the age where he is interested in attending more social outings, and is already talking about dating. I know he'll be able to go on movie dates as more movie theaters provide captioning. The advancement of technology has broadened communication accessibility for my boys.

My parents have also shared their experiences and guidance with their grandsons. Sharing their experiences of hearing loss back in the day has made my boys realize the huge growth in resources for the hearing loss community and the good fortune they have in this day and age.



The Wathen family, left to right: Tristan (14), Diane, Lucas (9) and Blake

My mother, Teri, has been a vital member of the growth of our Walk4Hearing community. She envisioned a community where individuals and families could share their struggles, experiences, and stories. She envisioned a community that would assist each other, care for each other, and support each other. The Walk4Hearing has been a positive experience for families who are involved with hearing loss in some way. There is someone at the Walk that everyone can relate to. The Walk4Hearing has been a great way for my family to be connected to the hearing loss community, to take pride and to press on.

The Wathen family lives in Meadows Place, Texas and participates in the Houston Walk4Hearing.

The Young Family: It Just Depends on Your Perspective

Our family of five is just like any other family—except you can hear us coming from a block away. With two members of our family with a hearing loss, we just naturally talk louder. My husband was born with a severe hearing loss which is hereditary. His sister, mother, aunt, and grandfather all have a hearing loss. With such a strong family history, we knew there was a good chance our children

could be born with a hearing loss.

When our first two girls were born, the state of California did not require newborn hearing screening at birth. As an educator, I knew the importance of early intervention and insisted on having them screened immediately.

Our second daughter, Kaitlyn, failed the newborn screening test and was identified as having a mild-to-moderate hearing loss at two days old. My husband and I didn't view hearing loss as a disability. We saw it as an opportunity to experience the world from a different perspective.

Kaitlyn received her first set of hearing aids when she was six weeks old. Her earmolds were the size of a dime. At six months the local school district began speech services. It was a lot of fun trying to keep hearing aids on an infant.

In 2008, we moved back to Michigan where Kaitlyn was enrolled in the Redford Union School's Oral Program for Children with Hearing Impairments—the same program my husband attended as a two-year-old. Through this program we were introduced to the Walk4Hearing, and as a family we attended our first Walk in 2009. When Kaitlyn began elementary

school she was mainstreamed as she was above grade level in all areas. The fact that she had access to hearing the world at such a young age allowed her to develop academically without any delays. We also had the benefit of family history, which allowed us to detect the issue early and give her the needed support.

It is wonderful to attend the Walk as a family, as both my husband and daughter have a hearing loss. While I and my other two daughters, Alexa and Nicole, do not have a hearing loss we receive so much support from the Walk. It is powerful to experience the joy from so many people who are impacted daily by hearing loss. There is such excitement before and during the Walk. We are constantly amazed by how many people put forth so much time and energy to help make it successful. It is also a great opportunity for my daughter to see that there are other kids and adults, other than those in her family, who have a hearing loss just like she does.

We are always excited to share our story of having multiple generations of hearing loss at the Walk4Hearing and how early identification can lead to providing the proper support and resources to give children and adults access to the world around them.

The Young family lives in Livonia, Michigan and participates in the Southeast Michigan Walk4Hearing. HLM



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The Young family, left to right: John, Kaitlyn (10), Alexa (13), Nicole (8), Karen, and Izzy, team mascot

Step Up for People with Hearing Loss and Communication Access!

The HLA Walk4Hearing is issuing a Call to Action, not just for walkers, but for all 48 million people in the U.S. who have a hearing loss, to step up and advocate for better communication access for themselves. It is our goal to start the conversation and provide tips for both those with or without a hearing loss to better communicate. By providing suggestions and information we hope to inspire and encourage people to advocate for better communication access.

We invite people to share their photos, ideas and success stories of how they are taking action by posting them on the Walk4Hearing Facebook page at facebook.com/walk4hearing and on Twitter @Walk4Hearing using #CommAccess, or email them to CalltoActionWalks@hearingloss.org with "Call to Action" in the subject line. Go to walk4hearing.org for more information.

