

Hearing MAGAZINE Loss

July/August 2009

Jennifer Cheng

*Racing With
(Not Through)
My Hearing Loss*

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Hearing MAGAZINE Loss

Volume 30, Number 4

July/August 2009



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Howard E. "Rocky" Stone
(1925-2004)

In 1979, Rocky Stone founded the organization as Self Help for Hard of Hearing People (SHHH).

The thinking behind the self-help philosophy for SHHH was to enhance each of us as human beings. Hearing loss was an important but secondary consideration. Once we accept responsibility for ourselves, we have to learn to love ourselves, and then, each other. —Rocky Stone



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By Brenda Battat



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From the Executive Director's Desk



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When I first came to HLAA over 20 years ago (SHHH as it was known then), the staff had to sign up to use the one computer we had in the office. The staff person responsible for fundraising got first dibs and the rest of us had to put our names on a time slot for that day and wait our turn.

We communicated with our members mostly by snail mail letters, typed on a typewriter, filed everything in hard copy that was kept in order by a volunteer, and researched topics and inquiries in our "library" of books on hearing loss slowly accumulated over the years. The only relay service our members used to reach us by phone was the traditional TTY—text telephone—with the roll of tape that recorded the conversation. That was 1989.

Fast Forward to 2009

The library at our office is about to become a storage closet. When the power goes out staff is at a loss as to what to do without access to their computers. Our members contact us through captioned telephone, most inquiries come in by e-mail, we do our research online, and staff communicate via inter-office messaging. With one click we can send out an online communication to thousands of people all at once, "meet" in chat rooms on different subjects, refer inquiries to resources on our website, post videos to our website and YouTube, set up blogs, and network on various professional and social networking sites.

Times have changed. Even in a small non-profit organization staff and volunteers are "on" 24/7. On vacation we no longer completely turn off and relax as there is always the urge, if not the feeling of obligation, to steal a quick look at our BlackBerrys. We say it is to prevent that pile up when we return but maybe we are really just addicted and cannot resist opening that new e-mail that just came in that always has an element of fascination to see what it says.

Today at our weekly staff meeting one of the topics was "Twitter." Twitter is a popular free social messaging utility for staying connected in real-time. Now, the way to be known is to "tweet," apparently a new verb entering the lexicon. Fortunately we have a staff person who keeps us on our toes to make sure we are up-to-date with the latest online applications and ways of communicating.

Just as some of us are getting used to the HLAA group on Facebook, she introduces Twitter into the mix and informs us that we are limited to 140 characters and that users sign up to follow other users whose tweets they enjoy. Some of us are pushed into it screaming; others just get it, and others, I for one, see the light and are willing to admit that it is great for marketing. So join HLAA on Facebook and Twitter and whatever else arrives on the scene! 

Brenda Battat is executive director of Hearing Loss Association of America and wears both a hearing aid and a cochlear implant. She lives in Bethesda, MD, with her husband Joe. She can be reached at battat@hearingloss.org. Read Brenda's blog at www.brendabattat.blogspot.com.

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By Jennifer Cheng



One of my greatest fears in life is to live too conservatively. When I was a child, I wanted to be the best. I was the fastest runner in the third grade (I beat the fastest boy), the school record holder for jump roping consecutive double-unders (112), the quickest one to finish my math tests (I blame the Asian parents for this one), and naturally, the teacher's pet. Nothing seemed to faze me. If the challenge presented itself, I'd take it without hesitation. I believed that I could achieve anything.

But then I grew up.

Upon reflecting over the last 15 years of my life, of which I've been diagnosed with progressive sensorineural hearing loss for 10, I've realized that my hearing loss has played a very significant (if not dominant) role in the person I've become today. I believe that my hearing loss should have been

observations were correct, but their inferences were not.

I Wish They Had Known the Truth

I also wish I had known the truth because it would have explained many questions for which I couldn't seem to find a satisfying answer. I was oblivious to the things I missed. I wasn't trying to be rude or mean; I didn't hear the conversation and completely missed the friendly gesture. I preferred the front of the bus because the back was always too loud and overwhelming for me, and I couldn't seem to decipher words and context without exhausting myself in doing so. I sat in the front of the class because I paid better attention (now I know it's because I could hear the teacher better).

Even with my very expensive, carefully-chosen, self-purchased, and

my friends joke. If only I could turn up their enunciation or my speech recognition.

Gathering Stats

I am an epidemiologist (someone who studies the patterns of diseases and their burdens—epidemics, endemics, pandemics, etc.), so naturally, I love statistics. In my short experience as a person who is hard of hearing, I've compiled a personal mini list of quick facts. Today 36 million Americans are living with a hearing loss to some degree. Many people in the world who have a hearing loss will never be diagnosed. Hearing loss is considered an "invisible condition," and there is still a stigma attached to the condition. My own relatives refuse to get properly tested or will flat out refuse to wear hearing aids.

Racing With (Not Through) My Hearing Loss

Hiding behind fear didn't get Jennifer Cheng where she is now. She shares her insights about living, working, and competing with a hearing loss.

diagnosed when I was in fourth grade when I failed the hearing test for the first time, but I didn't start wearing hearing aids until I was 17 years old—exactly two months before I started college at Gonzaga University in Spokane, Washington.

During middle and high school, I appeared to fit in well socially and academically, but I realized later that both appearance and reality can be deceiving. I learned years later that people thought I was arrogant, cold, and unfriendly upon their first impressions of me. They noted that I would turn away when they talked to me. They observed that I always sat at the front of the bus (not in the back with the cool kids). They assumed that I was always the teacher's pet because I sat in the first two rows in class and tried to actively participate. Their

relatively new hearing aids, I continue to face similar challenges every day. My challenges now have evolved from the classroom to the conference room, from the bus to the car, and from my peers to my colleagues and friends. I still struggle with self-advocacy, but I try not to let my hearing loss be an excuse to avoid life's obstacles. I will never have normal hearing, but I can minimize the consequences of having a hearing loss.

I'll never stop getting exhausted from participating in group conversations, but I can ask my friends to choose a quieter environment where I can see everyone's faces. No matter how nice my hearing aids are, I will always have difficulty carrying phone conversations. I will always miss certain syllables and some of the words in a sentence. "Turn up the volume,"

Ten years ago, hearing aids cost me \$3,000 for the pair at a local Costco hearing aid center. My hearing aids now are my third pair, and they are three years old; they cost me \$6,000. To this day, I am paying all of these expenses out-of-pocket. I've joked with my friends that I could have the road bicycle of my dreams for that price (or any car, for that matter), but instead I opted for better hearing! I should get my priorities straight.

Four years ago when I worked at the Hearing Loss Association of America in the national office, I learned about the Hearing Aid Tax Credit bill (HR 1646). At the time of this writing it has 69 sponsors in the House of Representatives and has been introduced in the Senate. Just a few years ago, TV captions were not

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Racing *continued from page 9*

required for major television stations. Cell phones gave me a headache because they gave feedback into my ears when placed too closely to my hearing aids because of the frequency incompatibilities. Today cell phone companies are required to have a selection of phones that are hearing aid-compatible. Alas, I have a new excuse to upgrade my phone!

Hearing Loss: A Unique Experience to Each

Each hearing loss experience is unique to the person, and it cannot be recreated by anyone else. No matter how much you try to find a common understanding of what hearing loss means to a person, it is impossible. I don't pretend to understand what anyone else is going through, nor do I expect others to understand what I'm going through. The key, however, isn't to understand me; it is *trying* to understand me. My family, friends, and coworkers are extremely supportive, and for that, I am grateful.

Ironically, I am my own weakest link because I haven't always been accepting of my hearing loss. When I was diagnosed 10 years ago, I knew nothing about the condition. There was no history of hearing loss in my family—other than the hearing loss my grandmother had which was associated with normal aging. I was 17 years old and two months away from leaving for college. I was neither rational nor accepting of the condition. During the summer of 1999, I remember that this news was both unwelcoming and heart-breaking. Not really able to grasp the reality, I was on autopilot.

For the sake of vanity, I bought the smallest pair of hearing aids that could fit into my ears. Despite that, my hearing aids spent most of their first two years in the original box in the back of my desk drawer. I went through the usual cycle of denial and acceptance of my hearing loss, but since then, I'd like to believe that I've

matured and grown a lot. I've learned to accept the probable future of my type of hearing loss—a progressive sensorineural hearing loss—and that I might lose the majority of my hearing one day. Although it has taken me a long time to accept my condition and all of the uncontrollable factors that come with it, I've grown a lot with the help and support of everyone around me.

Since then, I have learned how to personalize my hearing loss experience. It was clear that I faced challenges that my peers did not. On the flip side, I'm sure that others face challenges that I do not. The solution was simple: do whatever was necessary to minimize the barriers and understand that my experience might never be the same as that of my peers. More importantly, I reminded myself not to surrender to my fear of living conservatively just because I was afraid of its challenges.

Competitive Racing

Bike racing is one of my biggest achievements and simultaneously, one of the biggest challenges in life. It has presented itself with numerous challenges (physically, emotionally, and hearing loss related), I love it anyway. I am a competitive road racer. I race my heart out almost every weekend for seven months a year, and although I don't get the same media attention as Lance Armstrong, the sport is no less demanding, competitive, and rewarding. I haven't won the Tour de France seven times, announced an attempt to win an eighth time after retirement, published books, and survived testicular cancer like Lance.

However, I have raced with professional women, won some local races, spent countless hours training on the bike, and spent many weekends with my teammates on the road. I've spent my time in the hospital's shock trauma room, crashed in races, suffered from numerous asthma attacks, and I have scars on various parts of my body from road crashes,

“ Bike racing is one of my biggest achievements and simultaneously, one of the biggest challenges in life. It has presented itself with numerous challenges (physically, emotionally, and hearing loss related), I love it anyway. I am a competitive road racer. ”

stitches, and other fond memories. The sport is clearly not for the faint-hearted.

As if the sport wasn't challenging enough, I have an additional personal battle unique to me because I have a hearing loss. I do not hear people well while I'm riding my bike. The wind resistance is unbelievably difficult to overcome. Trying to hear on the bike is 20 times worse than trying to hear people in a loud bar. I can't hear any of the conversations that take place around me when I'm traveling at 25 mph in headwind. Did I mention that they are only inches away?

Sometimes I wear SlipStreamz, which are little ear covers that are designed to block the wind when people train with headphones. I use them simply to block the wind. Luckily for me and those around me, I sing all the songs that I jam to while exercising and training. When I'm really happy, I sing them loudly too! Unfortunately, they are terribly hot and uncomfortable to wear in 100 degree weather. They are not aerodynamic (if you've ever seen the funny helmets cyclists sometimes wear, you'll understand how important this factor can be). They do not provide good ventilation as does my \$150 helmet. Also, they are far from flattering, and I, like most road cyclists with pretty bikes, am vain. So sometimes, I opt not to use them. I have a great difficulty hearing people talk while I'm on the bike no matter what, but without the SlipStreamz, I suffer more than with.

Racing with a Hearing Loss

As a bike racer, it is crucial for me to hear what's going on in a race because how the race plays out is heavily dependent on the strategies, tactics, and communication of the team and those around them. I have taken the initiative to notify all of my teammates of my hearing loss, so they know that they need to ride beside me before yelling out warnings or strategy changes. Unfortunately, that is truly disadvantageous. Yelling out conversations during a race is like

“ It saddens me to learn that all baby boomers will now ‘inevitably’ suffer from a degree of hearing loss by the age of 50. I read this in *The Washington Post* a year ago. ‘Inevitably?!’ Wow. As a public health professional, this news is not only alarming, but frustrating. I see people driving around in cars with their stereos cranked up so loudly. I feel a similar wave of sadness when I’m standing next to a person who has his iPod playing so loudly that I can hear it. Honestly, I can hear the music at that volume. So many people cannot appreciate their gift of hearing, and meanwhile, I would trade anything to have it. ”

having a coach yell out the winning play in the last 15 seconds of a basketball game. Everyone hears it, and it's no longer a “winning play.”

I miss so much in races, and the good thing is that I'm aware that I miss a lot. The bad thing is also that I'm aware that I miss a lot, and I will continue to miss these things. I'll be the last to know when the person behind me starts shifting gears in preparation for a forceful attack. Everyone else will be able to hear the shifting and respond accordingly before the rider even fires off. I'll miss out on the so-very-informative conversations that are overheard by other teams during races. I once missed the announcement that our race was cut short an entire lap because the officials announced it by voice, but the change was not reflected in the lap count (obviously, I rely heavily on visual warnings and signs during a race). Recently, my team has discussed purchasing and using radios during the races so that we can receive instruction from our coach and directors on the sidelines. I wear In-The-Ear (ITE) hearing aids, so the idea was immediately followed by internal concerns.

What Can I Do to Minimize My Limitations?

I have to compensate in other ways. I have to be extra strong, so that I can chase people after an attack (when a person “attacks” the main group—the peleton—and tries to leave everyone else behind). It might take me more energy to respond because I'll have reacted three seconds too late, but it's okay because I know what I need to do.

I can't overhear conversations that go on during the races, so I have to rely more heavily on body language. I try to read faces more, notice little signs for when people are suffering, and I have to be alert all the time—although it's pretty hard not to be when you are riding a bike six inches away from the person next to you on both sides and in front and behind you at 30 m.p.h.

Fortunately, by not hearing the side conversations, I also get to miss some of the drama, yelling, and fighting that goes on too! (You may be surprised by how dramatic cyclists can be, so for that, I am very grateful!) As for communication between my teammates and me, non-verbal communication is really important for us to practice and master.

Through these experiences, I have learned to self-advocate what I need to make my unusual situation safer and better for everyone. I have taken the initiative to notify the entire group of USCF (United States Cycling Federation) officials for the Mid-Atlantic area of my hearing loss, and I bring a yellow flag for them to wave for premium laps (a race within a race) and for the last lap—also called the bell lap—because I can't hear the bell that they usually use to notify us.

When I ride with new people, I try to tell them that I have a hearing loss. My entire team is well aware of my condition as are most of the racers I see on a weekly basis. I have to admit that it has not always been easy because I ride with new people all the time, and it is both difficult and sometimes cumbersome to remember to tell people that I have a hearing

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Racing *continued from page 11*

loss. It's about as annoying as telling every single person that walks down the street, "I have a hearing loss" to anticipate any possible future misunderstandings. As a result, sometimes people who don't know me think that I am arrogant because I'm not chatty on training rides. I race almost every weekend, so people are beginning to know who I am—especially when I win money for the team!—and it all works out in the end.

I use my hearing loss as a means of educating others around me too. It saddens me to learn that all baby boomers will now "inevitably" suffer from a degree of hearing loss by the age of 50. I read this in *The Washington Post* a year ago. 'Inevitably?!' Wow. As a public health professional, this news is not only alarming, but frustrating. I see people driving around in cars with their stereos cranked up so loudly. I feel a similar wave of sadness when I'm standing next to a person who has his iPod playing so loudly that I can hear it. Honestly, I can hear the music at that volume. So many people cannot appreciate their gift of hearing, and meanwhile, I would trade anything to have it.

Despite all of the barriers and challenges, I've learned that if I am comfortable with wearing hearing aids, and that if I take the initiative to let people know that I cannot hear when they speak behind me or when they mumble words or are in the dark where I cannot lip-read, I find that most people are very understanding

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U.S. Public Health Service Officer Basic Training in Lansdowne, VA, January 2009. From left: LT Elizabeth Hoang, CDR Patrick Denis, Jennifer Cheng and CDR Kimberly Elenberg

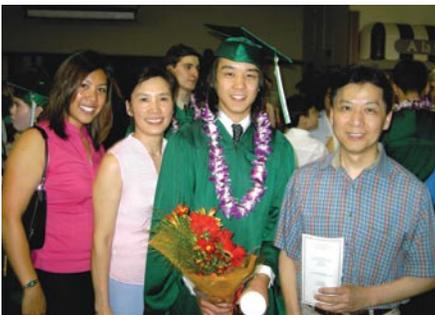


In 2007, in Washington, D.C., Jennifer spoke on behalf of the Hearing Aid Tax Credit Bill, of which Rep. Chris Van Hollen is a co-sponsor.

Below: Team CycleLife powered by Specialized members—from left: Jennifer Cheng, Christina Briseno, Leslie Jennings, Melanie Schwartz, Sonia Evers, Sara Zeigler, Michelle Hart (not pictured: Robin Zimmerly and Wendy Ulmer)



and will accommodate my needs. I used to worry that people will judge me differently if I tell them about my hearing loss too soon into the relationship, but when I have to wear hearing aids every day to our team rides and my hair is in a ponytail, it's hard to hide it. I realized that in the end, it was all in my head. I don't need to hide it. I haven't lost any friends because of my hearing loss. People don't treat me like I'm strange or different. We live in the 21st century where many people—especially the younger population—are very accepting of many different things.



Jennifer (left) with her family. From left: Jennifer, Stella (mother), Jasper (brother), and Joseph (father).

On the contrary, people sometimes treat me *too normally* meaning they think hearing aids are magical devices that give me normal hearing. Hearing aids help me to hear better, but they don't "fix" my hearing. They are not the equivalent of contact lenses for the eyes. They are often surprised and confused when I still have to ask them to repeat sentences, and they don't know why I am usually quiet and cannot jump into conversations. Until recently, I didn't realize that I

process some sentences a split second after it's said because I fill the blanks of words that I missed by putting it all into context.

Fear is a challenge everyone faces, but since I refuse to hide behind it, I must overcome it. I accept that my hearing loss gives me certain limitations, but it shouldn't prevent me from achieving great things in life. As James Baldwin once said, "Not everything that is faced can be changed, but nothing can be changed until it is faced." 🗣️

Jennifer Cheng is an infectious diseases epidemiologist for the United States Public Health Services. She graduated from George Washington University with a Master of Public Health degree in International Health in May 2006 and has since been working at the Division of Immigration Health Services. She was born and raised in Seattle where her family and childhood friends still reside. Jennifer is a competitive road cyclist for Team CycleLife powered by Specialized, a proud promoter of women's cycling and racing in the Mid-Atlantic Region. Jen was diagnosed with a progressive sensorineural hearing loss at the age of 17, and has been wearing hearing aids ever since.

She received the HLAA Outstanding Young Adult Award at Convention 2009 in Nashville this past June. She can be reached at cheng.jenjen@gmail.com.

Jennifer Cheng Joins Walk4Hearing™

Last year, I participated in the National Capital Area Walk4Hearing™. There were many people in attendance, and some even traveled from the New England area! The weather was beautiful, the people were excited, and even the scenery along the trail made for a pleasant walk. Best of all, there was pre-walk and post-walk food and drinks ready to turn our caloric deficit into a caloric surplus. I learned some interesting facts by reading the fact posters along the walk. And, final celebratory remarks HLAA Executive Director Brenda Battat were communication accessible with real-time captioning and audio loop.



I had a wonderful time joining a group that united for this wonderful cause. As a person with a hearing loss, I know how important it is to educate, promote and support programs for people with hearing loss on the local and national levels.

Join me in walking this year in the Washington, D.C. Walk4Hearing™, October 17, at the Tidal Basin.

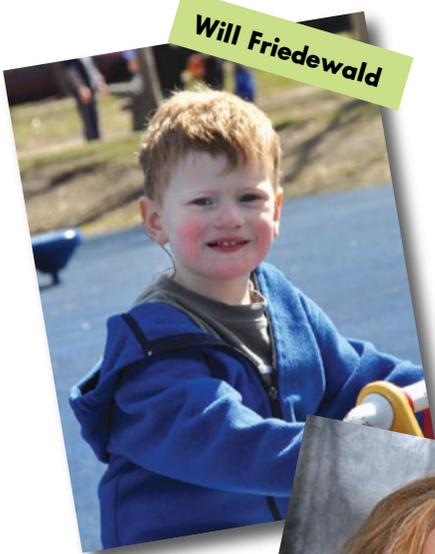
Most exciting is that Redskins Reed Doughty is honorary chair this year. Together, we can represent all age groups while we step up to create awareness about hearing loss.

To learn more information about the Walk4Hearing™, go to www.hearingloss.org.





The 2009 *Walk4Hearing*™ season is in full swing. Having completed spring walks across the country, we are now heading into the fall walks. To find out about the fall walks, go to www.walk4hearing.org



Will Friedewald



Lexi Harman



Rory Kuczek



Maya Bittner



AJ Best

Little Feet Step Up to *Walk4Hearing*™



By Ronnie Adler

The Hearing Loss Association *Walk4Hearing*[™] program has grown in many ways: from six walks in 2006 to 21 walks in 2009, with over 5,000 walkers, hundreds of community volunteers, gained many national and local sponsors, and raised \$1 million for local and national programs and services.

We have alliances with nonprofit hearing loss-related organizations and schools all across the country. The most exciting developments are the families of children with hearing loss who are joining us. Each year, we see more families walking.

Many of these families had no idea where to go when they first discovered their children had hearing loss. Others received all kinds of wonderful information from hearing healthcare professionals; information that truly helped them cope with their child's hearing loss. Now all of these have come together. Getting involved with the *Walk4Hearing*[™] is a way to give back and meet others with a hearing loss and realize their children will have bright futures even with hearing loss.

Here are five stories from parents who have participated as a family in walks around the country. They are written from the heart.

John Friedewald

Chicago *Walk4Hearing*[™]

Team: **Walk for Will**

When our son Will was around ten months old, we learned that he had a profound hearing loss. This was our first contact with the hearing loss community and we did not know where to start. But we knew, through the wonderful team at Children's Memorial, that we had options, and that Will had a very bright future in large part because of early detection. What helped us most was the support of other families walking the same path.

When we first participated in the *Walk4Hearing*[™] in 2007, we realized that we not only were going to meet a wonderful new group of people, but that those people were organized and motivated to make a difference in the lives of people with hearing loss. And the outpouring of support from our friends and family let us know that we were not walking alone. It is amazing to me, how a simple event can be so symbolic and be such a great comfort to the families of children with hearing loss.

Katy Kuczek

Rochester (NY) *Walk4Hearing*[™]

Team: **Rory Cole Walkers**

When my daughter uttered her first word, 'bike,' I noticed it had a strange resonance to it. But it would take three more years to officially discover that she had hearing loss as the result of tests recommended by her speech therapist. Unfortunately, newborn hearing screening had not yet been instituted, or else we would have known from day one.

Just before her fourth birthday, Rory was fitted with a digital hearing aid in her right ear, which has a moderate-to-severe hearing loss. She was fitted with a second digital hearing aid 18 months later, again at the recommendation of her speech teacher. The teacher made a convincing argument for balancing the sound intake, even though the hearing loss in Rory's left ear was mild-to-moderate.

Fast forward to today. My daughter is a bright, mainstreamed, fourth grader. We chose to participate in the *Walk4Hearing*[™] three years ago because Rory was proud of her hearing aids and wanted to educate her friends about hearing loss. Three years running now (and she and her little brother literally run the walk, at least the first half of it), we continue to participate, because it's fun for the kids, our family and friends support us by being part of our team, and it's a wonderful community event with the new friends we've made through HLAA.

Robyn Bittner

Dayton (OH) *Walk4Hearing*[™]

Team: **Maya's Magic Ears**

Maya is full of life and lives each day to the fullest! Maya was my first child and we were thrilled to have started our family. Maya failed her newborn hearing screening in the hospital. But she adapted to her hearing loss very well and continued to reach all of her milestones and even babbled and appeared to understand everything we were saying.

My "Aha!" moment occurred when Maya started preschool and was not talking as clearly as the other kids in her class. My husband and I finally needed to get to the truth and find out if she did, indeed, have a significant hearing loss. The diagnosis came in that Maya had genetic, moderate-to-severe hearing loss in both ears and would need to wear hearing aids. The day we put the hearing aids on Maya was such a wonderful day. She took to them immediately because she can hear so much better. We refer to Maya's hearing aids as her "Magic Ears."

Maya's hearing loss has never held her back in life. Her favorite hobby is swimming. She is a fish in the water! Maya amazes me every day. Her hearing loss has shaped her to be the wonderful, energetic little person that she is today. We have always viewed her hearing loss as more of a positive than a negative!

We are so excited to have our family involved in the *Walk4Hearing*[™] in Dayton this year. I feel that it is so important for families with children to get involved with the Hearing Loss Association of America. My biggest word of advice to parents with a child with hearing loss is to try to make it a positive rather than a negative thing in their life. Kids will pick up on so much, and as long as the parents remain positive, the child will 'live life to the fullest!'

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Walk4Hearing™

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Lauren Harman

Garden State (NJ) Walk4Hearing™

Team: **Go Team Lexi**

I learned about my daughter Lexi's hearing loss when she was two. At first I thought she was just being stubborn and wasn't 'listening' as opposed to wasn't 'hearing.' After visits to several audiologists, we learned that she had a bilateral hearing loss which could be progressive. This was unfathomable to me. How could my beautiful daughter potentially lose all of her hearing?

I went through many stages of grieving, denial, then anger, then gradual acceptance. As part of my own personal therapy, I started researching like crazy, looking for any information I could find. I came across the Walk4Hearing™ and decided this would be a good way to continue my quest for information and inclusion for my daughter. I signed up with my husband, son,

and daughter. I thought it would be a good family thing for us to do.

When I mentioned the walk to family and friends, I could not believe the support people provided. Our small team took on a life of its own. People joined our team and we received so many generous donations. It was amazing and showed me how much people cared. The day of the walk was great—we had perfect weather and a great team. The best part of the walk for me was watching Lexi, then age four, lead the team as if she was in a parade, proud as can be, shouting out, "Go Team Lexi!" She was so delighted that everyone was there for her when she marched, ran, and skipped through the whole walk while leading her team. Watching her was so incredibly heartwarming because she knew just how truly special she was that day.

Theresa Best

Southeast Michigan Walk4Hearing™

Team: **The Warriors**

When AJ was age five he had an ear infection that took several rounds of different antibiotics to heal it. I noticed during the course of treatment that he was not responding to me the way he normally would. Since I come from a family where several members have hearing loss, I immediately contacted the doctors for more in-depth hearing tests. The results showed that AJ had a hearing loss. At this time the doctors and

audiologist did not feel AJ needed to wear hearing aids. Two years later, another infection set in. Although, this one was more easily treated, the signs of hearing loss could no longer be ignored and he was fitted with hearing aids that he has been using for almost two years.

As a mother, I was worried about school and social settings. However, the amazing AJ showed his true colors. He never looks at himself as different. He just keeps on doing what needs to be done. AJ never thinks of his hearing loss as an excuse. His teachers tell me what a great student he is. AJ has also been wrestling and playing football for three years. Even though his hearing loss makes these sports more difficult, he does not let it stop him. He has an awesome attitude and great heart!

AJ was the co-captain of The Warriors Walk4Hearing™ team. His goal is to help others with hearing loss. He got others involved in this year's walk and his wrestling team supported him as he walked to help others with hearing loss. **TTM**

Ronnie Adler is the National Walk4Hearing™ manager. For more information about having a walk in your town, or getting involved, e-mail her at radler@hearingloss.org, or go to www.walk4hearing.org.



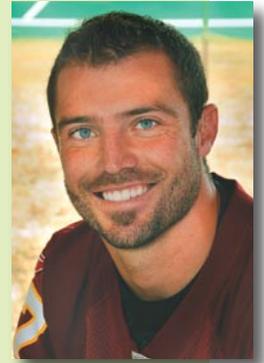
Our V.I.P Walk4Hearing™ Chairs

Reed Doughty, Washington Redskins #37 • Honorary Chair, Washington, D.C. *Walk4Hearing™*

Reed Doughty, defensive player for the Washington Redskins is no stranger to hearing loss growing up with a hearing loss and wearing hearing aids for the first time in the 2007 NFL season. When we asked him what attributes put him in the position of strong safety for the Redskins, he said, "Toughness, tenacity, and hard work."

Reed applies those qualities to everything he does, from being a scholar athlete in college, to his career with the Redskins, to his home life as husband to Katie and father to Micah and Caleb. He was named the team's Ed Block Courage Award winner for 2008. Reed is pleased to serve as the 2009 Honorary Chair of the Washington, D.C. *Walk4Hearing™* to bring about awareness about hearing loss, its implications and causes. He comments; "Hearing loss might have a stigma sometimes, but I am in need of hearing enhancement. I'm going to wear hearing aids. I hope others will get the help they need."

The event will be held on October 17, 2009, at the Tidal Basin. For more information go to www.walk4hearing.com. For more information about Reed Doughty, go to www.washingtonredskins.com or read the interview with him in the November/December 2008 *Hearing Loss Magazine*. (Article available on www.hearingloss.org.)



Mike Orscheln, President and CEO of Phonak Systems • Business Team Chair, Chicago *Walk4Hearing™*

In its third year, Chicago area volunteers from HLAA chapters and community groups have brought together hundreds of people to *Walk4Hearing™*. This year, HLAA is honored to have Mike Orscheln, president and CEO of Phonak, serve as Business Team Chair of the Chicago Walk4Hearing. In his role, Orscheln will lead by example by having a Phonak employee team and enlisting other local businesses to sponsor the walk.

Orscheln comments, "At Phonak, we are committed to opening up the world of hearing to those with hearing loss through the development of and manufacture of world-class digital hearing systems. The Hearing Loss Association of America (HLAA) shares our mission, that's why Phonak is proud to be a national sponsor of their *Walk4Hearing™* program. It is also why I am particularly honored to serve as the Business Team Chairman for the HLAA's Third Annual Chicago 5K (3.1 mile) *Walk4Hearing™*."

The Chicago *Walk4Hearing™* will be held on Sunday, October 18, 2009, in Lincoln Park.



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10:00 am Make a reservation



12:05 pm Change doctor appointment



5:45 pm Call a friend

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www.siprelay.com

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10

When You Have Both Hearing and Vision Loss

Are you hard of hearing and also have vision loss? Do you want to meet other people like you? There are resources available for you.

By Elizabeth Spiers

Some people acquire a vision loss later in adulthood because of common causes of vision loss such as glaucoma or macular degeneration. Others are born with both vision and hearing loss, or lose these senses in early childhood through a variety of causes such as genetic syndromes, birth defects or optic and auditory nerve damage from birth trauma or illness. People may have a range from mild to total hearing and vision loss.

Common Causes of Vision Loss

Macular Degeneration:

affects the macula, the center of the eye that allows people to see fine details.



Most at Risk: Caucasians, females, those with a family history of macular degeneration, smokers, people who are obese. Also senior adults may experience this condition (thus called age-related macular degeneration).

Symptoms: cloudy, blurry vision; colors look faded; problems with glare; poor night vision; double vision or multiple images in one eye; frequent prescription changes

Cataracts: a clouding in the eye that affects vision. Clouding can affect one or both eyes. A cataract is a build-up of proteins that clump together and clouds the lens of the eyes.

Most at Risk: people with a family history of diabetes, smokers; prolonged exposure to sunlight

Symptoms: cloudy, blurry vision; colors look faded; sensitivity to bright light; poor night vision; double vision or double images in one eye; frequent prescription changes in glasses or contact lenses

Glaucoma:

caused by damage to the optic nerve because of increased eye pressure.



Most at Risk:

people with a family history of glaucoma, persons over 60 years of age and African-Americans and Hispanics over age 40.

Symptoms: difficulty seeing at night; loss of contrast; loss of peripheral vision

Diabetic Retinopathy: damage to the blood vessels in the retina, caused by changes in these vessels. With some people, blood vessels will swell and leak fluid. With others, abnormal new blood vessels will grow on the surface of the retina, the light-sensitive tissue at the back of the eye.

Most at Risk: people with Diabetes Type 1 and 2 or those with a family history of diabetes

Symptoms: No symptoms in the early stages (can only be detected through a dilated eye exam). Blurred vision occurs in the later stages when the macula swells from leaking fluid.

Optic Atrophy: damage to the optic nerve. It can result if the optic nerve is not developed properly, or if it is damaged through too much pressure in the eye. In rare cases poisons, tumors or vitamin deficiencies can cause damage to the optic nerve. In some situations, the causes are unknown.

Most at Risk: people who have a genetic history of optic atrophy; people who are at risk of having too much pressure in the eye (such as glaucoma); people who may have tumors.

Symptoms: Blurred vision, abnormal peripheral vision, abnormal color vision, poor correction of the pupil in light, decreased brightness in one eye in comparison to the other.

Retinitis Pigmentosa: a gradual decline in vision because photoreceptor cells (rods and cones) die. Damage to the retina, as well as rods and cones of the eyes. The rods govern night vision, while cones determine how much peripheral vision a person may have.



Most at Risk: people who have a genetic condition for retinitis pigmentosa.

Symptoms: Night blindness, reduced or no peripheral vision; spots or "islands" in field of vision (usually in beginning stages); difficulty with color discrimination.

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Vision and Hearing Loss

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Usher Syndrome

About three to six percent of people in the hard of hearing communities have Usher Syndrome. This genetic condition combines hearing loss and retinitis pigmentosa (RP). Three types of Usher Syndrome exist: Usher 1, Usher 2, and Usher 3.

Below is a short description that outlines the three different types of Usher Syndrome.

Usher 1

- Person is usually born profoundly deaf; does not lose hearing later in life
- Some people may grow up in deaf community and use ASL for communication; others depend on speech and speechreading.
- Usually born with normal vision; starts experiencing night blindness usually in early teens
- Experiences peripheral vision loss in later years; age of onset varies.
- May or may not become fully blind
- Sometimes experiences balance problems

Usher 2

- Person is usually hard of hearing from birth; does not experience additional hearing loss
- Some use speechreading and residual hearing with amplification for communication; others may also use American Sign Language or other sign system
- Usually born with normal vision; experiences night blindness in early teens
- Usually experience peripheral vision loss later in life; age of onset varies
- Typically does not experience balance problems, although a very few may

Usher 3

- Person is born with normal hearing or mild hearing loss; loses more hearing later in life
- May use speech and speechreading for communication and hearing

assistive technology; others may or may not use American Sign Language or other sign system for communication

- Usually starts experiencing night blindness in early teens
- May experience peripheral vision loss later in life; age of onset varies
- May or may not become fully blind
- Typically may lose more hearing as person gets older
- Typically does not experience balance problems

Managing Your Vision Loss

A regular eye exam is very important, especially as the majority of adults with visual problems have more than one cause for their vision loss. Also, in some cases, vision loss can happen very gradually. If they are caught and treated early enough, the eye conditions can be prevented from becoming worse later. Check with your insurance company to see what ophthalmologists are covered under your insurance. In some cases, your ophthalmologist may refer you to a specialist.

If you find out that you are experiencing a decrease in your vision, you may benefit from certain devices that can help you maximize the vision you have. You can ask your eye doctor to refer you to a place where you can receive a low-vision evaluation, or you may be able to receive this evaluation in your eye doctor's clinic, especially if you see a low-vision specialist. You will have a chance to try out different devices such as magnifying glasses, reading glasses, closed circuit televisions (CCTVs) and other visual aids.

Maintaining Good Vision

- Get an annual eye exam.
- Wear sunglasses and a wide-brimmed hat or cap for protection from the sun.
- Stop smoking if you smoke.
- Exercise regularly.
- Consult your eye care professional before taking nutritional supplements.
- Maintain a healthy blood pressure level.

- Eat lots of colorful fruits and vegetables, and avoid too much fat in your diet.
- Wear eye protection when mowing the yard, working with power tools or playing contact sports.

Resources

You may also want to meet other people who have both vision and hearing loss. Below are some organizations and resources you can use to meet others and get more information about vision loss.

National Organizations

American Association of the Deaf-Blind

Silver Spring, MD 20910
301-495-4402 TTY/Videophone
301-495-4403 Voice
E-mail: aadb-info@aadb.org
www.aadb.org

The American Association of the Deaf-Blind is a national consumer membership organization of, by and for people with dual vision and hearing loss. They welcome people with all types and degrees of vision and hearing loss, as well as family members, professionals and other supporters. People can subscribe to a free monthly e-newsletter, *AADB Today*. Members can also receive a biannual magazine, *The Deaf-Blind American*. AADB provides education and outreach to the public, including legislators, manufacturers, businesses and government entities on the needs of people with dual vision and hearing loss. They also provide information and referral on deaf-blindness and its related topics.

AADB is famous for its national conferences, where people from all over the country can network and socialize with each other, and learn the latest in legislation, technology, programs and services.

American Foundation for the Blind (AFB)

New York, NY 10001
800-AFB-LINE
800-232-5463

afbinfo@afb.net
www.afb.org

The American Foundation for the Blind has descriptions of various eye conditions as well as resources for people who are blind or visually impaired on their website. The AFB also maintains a resource directory of agencies for people who are blind or visually impaired on their website, where people can get information on services in their area. It also hosts national conferences where people can meet to learn about the latest information for people who are blind or visually impaired.

Foundation Fighting Blindness
Owings Mills, MD 21117-2220
800-683-5555 Toll-Free
800-683-5551 TTY
info@FightBlindness.org
www.blindness.org

The Foundation Fighting Blindness has web-based information on different types of vision loss. It also publishes a newsletter and other publications, and does research on the causes of and possible cures or treatments for vision loss. In addition, it hosts national conferences, and has chapters around the country where people can meet to network and learn about the latest in vision loss.

National Eye Institute (NEI)
Bethesda, MD 20892
301-496-5248
www.nei.nih.gov

The National Eye Institute has informational materials and web-based resources on various eye conditions. It also provides information on research and legislation related to vision loss.

State and Local Deaf-Blind Affiliations

One excellent way to meet other people with vision and hearing loss is through a local or statewide association for deaf-blind people. The American Association of the Deaf-Blind has a listing of organizations around the country on its website.

People can go to www.aadb.org, and click on the resource link on the home page. They will be directed to a listing of deaf-blind associations. They can also contact AADB for information (listed on the previous page) if they have no access to the Internet.

Internet Resources

Many people with both vision and hearing loss can meet and network with each other through a variety of listservs specific to this population. Below is a listing of the larger and more popular listservs, and subscription information.

DB List—this is a listserv where people can discuss and share common experiences and frustrations of having dual vision and hearing loss. To subscribe, type in the subject header or body of your e-mail: Subscribe deafblind first name last name, and send it to listserv@tr.wou.edu. Leave out the "i" in deafblind. (e.g., subscribe deafblind John Doe).

Usher List—people who have Usher, friends, family and supporters can talk about having Usher, and share strategies and techniques for dealing

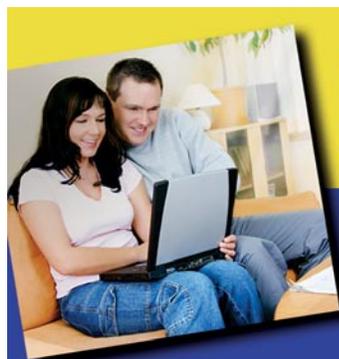
with Usher, as well as information on available resources. To subscribe, type in the subject header or body of your e-mail: subscribe Usher first name last name (e.g. subscribe Usher Jane Doe). Send this e-mail to listserv@tr.wou.edu.

AADB L—AADB-L is a listserv run by the American Association of the Deaf-Blind. One has to be a member of AADB to join. Here, people can offer feedback and suggestions about the services and programs that AADB provides. People can contact the AADB Office (listed on the previous page) for information on how to join AADB and the listserv. 

Elizabeth Spiers is director of Information Services at the American Association of the Deaf-Blind in Silver Spring, Maryland.



Information for this article was taken from the websites of the Foundation Fighting Blindness and the National Eye Institute (National Institutes of Health), listed above. Photos were taken from the website of the National Eye Institute (National Institutes of Health).



AMERICAN ACADEMY OF HEARING LOSS SUPPORT SPECIALISTS

Opening Doors, Changing Lives

The Academy has created an affordable online, self-paced, distance learning program for adults that focuses on the biological, medical, psychological, and social aspects of hearing loss. The broad curriculum has been developed by HLAA professional staff, members of the Academy Advisory Board, and other leaders in the hearing health professions. It consists of 4 online courses that focus on these topics: Introduction to Hearing Loss, Coping with Hearing Loss, Hearing Assistive Technology, and Advocacy Resources and the Law.

To register and for more information, visit our website at

www.hearingloss.org

Building Knowledge to Better Serve People with Hearing Loss...

By Lise Hamlin



Grace with the Speaker of the House Joseph Roberts, primary sponsor of assembly bill of Grace's Law, with Senator Marcia Karrow. Photo taken in December 2008 when the bill passed both Houses and would go to the New Jersey governor.



Last October 2008, the Grace's Law Team raised over \$7200 for Hearing Loss Association of America's Walk4Hearing™ and fielded one of the largest teams in the country, with 74 people walking that day.

Grace's Law: A Lesson in Advocacy

Jeanine Gleba discovered her health insurance plan did not include hearing aid coverage for her daughter Grace. She was flabbergasted. "What good is newborn hearing screening if children can't get proper amplification?" This is when a dedicated group of advocates jumped in.



On December 30, 2008, Grace's Law was signed by Acting Governor Codey. Far right is Grace's uncle, Chris Williamson, standing in for Grace who was away on vacation with her family. The girl next to Chris, Caitlyn D'Alessio, is holding Grace's photo. The children on the left are Kaitlyn and Tyler Weatherby. Assemblymen are standing in back.



On January 23, 2009, Grace meets Governor Jon Corzine for the ceremonial signing of the law.

There is no question that there are many wonderful hearing aids on the market, including newer aids with terrific new technology. Hearing aids with Bluetooth, hearing aids with automatic gain control, adaptive directional microphones, automatic telecoils, noise reduction and speech enhancement programs, are just a few of the features available in the newer generation of hearing aids.

All of this is great, but it comes with a cost—literally. Many hearing aids are without question expensive. The high cost of hearing aids is something that has long bedeviled people who depend on them.

The average cost of hearing aids in 1997 was \$971. That average increased to \$1,800 in 2004, and we know in 2009 many people regularly spend \$3,000 on a single hearing aid. One person contacted us because his 80-year-old mother had hearing aids that both gave out at the same time and was looking for financial help to replace those.

One mother reported that she had to choose which of her four children with hearing loss received hearing aids. With all those little ears to cover, that represents a serious dent in a parent's budget. Imagine, if you will, having to decide which of your children get to hear.

What to Do?

One way to address the problem is legislatively. Ten years ago Carol Granaldi, a long-time member of HLAA, spearheaded an effort to have hearing aids covered by insurance carriers for all who needed them in New Jersey. That legislation came to the attention of a mom with a daughter who had been identified in 1999 through New Jersey's newborn hearing screening program.

Jeanine Gleba discovered her health insurance plan did not include hearing aid coverage. Jeanine was flabbergasted. "What good is newborn

One mother reported that she had to choose which of her four children with hearing loss received hearing aids. With all those little ears to cover, that represents a serious dent in a parent's budget. Imagine, if you will, having to decide which of your children get to hear.

hearing screening if children can't get proper amplification?"

It's not easy getting legislation passed, as many advocates will attest to. The original bill never did make it out of committee. A new bill was introduced that focused on coverage for children. Still, it took many years of hard work to push that bill forward. Carol Granaldi became her friend and mentor during that time, but without a doubt it was her daughter Grace, now age 10, who helped this bill become law according to Jeanine.

Jeanine commented, "Grace has been visiting legislators' offices since she was a toddler! She has been signing letters since she could write her name. Once she was older she wrote her own letters to legislators and better still, she used her own voice and testified these past few years. She enlisted the help of fellow classmates to also write letters to the governor and legislators...I truly believe in the end it was *all* the children who came to testify that made the difference!"

If Grace was the person who put a face on the law, Jeanine was the person whose persistence pushed it along. She worked first for the bill as introduced in 1999, then for Grace's Law in 2002. She testified at committee hearings, mailed flyers with updates and advocacy action items to supporters, sent out e-mail bulletins, established a website with the help of a volunteer and gathered 8,200 signatures on an Internet petition.

Jeanine emphasizes that team work was essential to the effort.

Starting with her family and friends, she worked with others to build awareness and participation across the state. She enlisted the help of parents from every district in the state in sending letters to legislators. And she worked to get press coverage locally and eventually nationally with a spot on ABC's World News Tonight with Charlie Gibson. The Summit Speech School helped Jeanine and some mothers host an event in May 2008 that honored local legislators who sponsored the bill.

Last October 2008, the Grace's Law Team raised over \$7,200 for Hearing Loss Association of America's *Walk4Hearing*TM and fielded one of the largest teams in the country, with 74 people walking that day.

Grace's Law is Passed

After many long years of struggle, in 2008 the legislation passed both Houses and on December 30, 2008 it was signed into law. It was a very long time coming, but all that work did pay off. Jeanine credits help from the many others who worked with her, including Arlene Romoff, president of the Hearing Loss Association of New Jersey, Gary Kirsch, former president of Alexander Graham Bell Association, Pam Paskowitz of Summit Speech School, and many incredible families with children who need hearing aids.

As sweet as victory is, there is still more to be done. After the law passed, it became clear that many would not benefit: people who have self-funded insurance plans are not covered under the new law. Those left behind were severely disappointed they could not benefit from the passage of Grace's Law. Now they have a choice between fighting yet another legislative battle, or requesting each employer provide needed coverage directly.

"It's a national problem," Jeanine notes. "We need insurance industry reform to make hearing aids a standard benefit."

continued on page 24

Grace's Law *cont. from page 23*

Advocating for legislation is always a process that takes time and patience. Jeanine and her daughter Grace have shown extraordinary patience and persistence. In looking back, Jeanine says, "we persevered for many reasons...it reached a point where I couldn't quit because I didn't want to set a bad example for my three children. I wanted them to learn that dedication does pay off, patience is a virtue and most importantly it is important to do the right thing and fight the fight to make a positive difference in the world."

Jeanine and Grace and many others did make a difference. Now it's up to others to take the next steps. 

Lise Hamlin is the director of public policy and state development. She can be reached at lhamlin@hearingloss.org.



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How to Advocate for a Cause You Believe In

Be Patient, Persistent and Polite

- Be ready to knock on legislator's doors, go to hearings and committee meetings, and get to know the legislators.
- Put a face on the legislation: A child's name or a poignant story attest to how important the legislation is and how it impacts constituents in real life.
- Recognize and thank sponsoring and supporting legislators.
- Do your homework: research the facts behind supporting the law.
- Find a legislative champion.
- Work the media.
- Have a main contact person who really will respond to letters and e-mail.
- Build from the grassroots and keep on building.
- Build coalitions with other supporting organizations.
- Use the Internet—websites, Action Alerts, letter-writing campaigns, listservs all build the momentum.
- Be patient—it takes time to make change happen.
- Celebrate your victory: have a party of appreciation for all who worked on the legislation when it finally does pass! 

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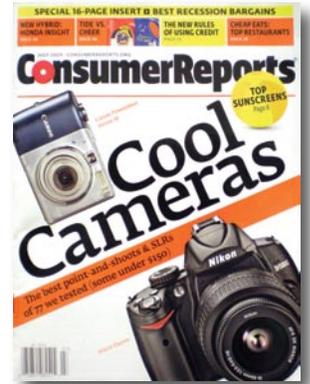
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HLAA Named as a Resource in *Consumer Reports*

“What is the Best Hearing Aid?” is the most frequently-asked question at the Hearing Loss Association of America (HLAA). Even though we have covered this topic in *Hearing Loss Magazine*, it pops up repeatedly. There never is a clear answer. In the July 2009 issue of *Consumer Reports*, the article, “Hear Well in a Noisy World: Hearing Aids, Hearing Protection & More,” cover the topic. It still remains nearly impossible to say which hearing aid is the best as hearing loss varies among individuals. However, it is an excellent article to which HLAA had input and is mentioned as a resource. The July article includes advice on choosing a good provider, types of hearing aids and features, and hearing protection. Be a smart buyer—follow up after the purchase is made. A shopping summary gives guidance on:

- Where to go for hearing aids
- What to expect from the provider
- What will happen during the first visit and what to ask for
- What should take place at the fitting visit
- What to do when you get home with the hearing aids which does not include leaving them in a drawer



Checklist for Consumers

The *Consumer Reports* article online refers readers to a consumer checklist drawn from Consumer Reports testing and shopping experience, their audiology consultants, and from the resources of the Hearing Loss Association of America. HLAA published “Purchasing a Hearing Aid: A Consumer Checklist” on www.hearingloss.org and in the May/June 2009 issue of *Hearing Loss Magazine*.

Where to Find the Article

The *Consumer Reports* July 2009 issue is available on newsstands now. The article on our website at www.hearingloss.org. 

Stay Tuned...Coming in the Next Issue

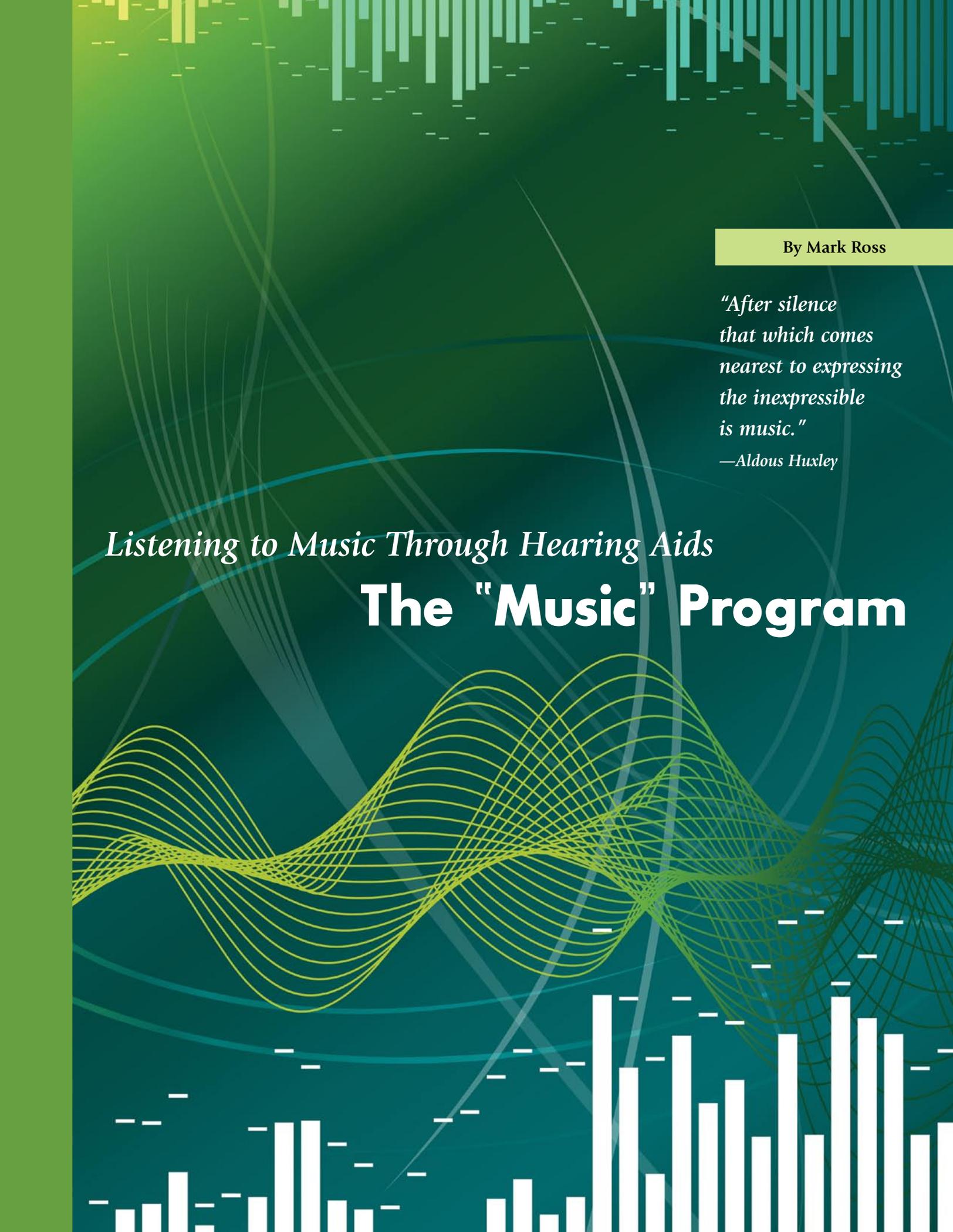


Convention 2009 Wrap-Up with photos
Read the Convention Blog now on www.hearingloss.org.

HLAA President Michael Stone will give his recap of the Board of Trustees meeting and annual membership meeting from Convention 2009 in Nashville.

Captain Mark Brogan, United States Army (Retired), talks about his injuries from Operation Iraqi Freedom, one of which is hearing loss.





By Mark Ross

*"After silence
that which comes
nearest to expressing
the inexpressible
is music."*

—Aldous Huxley

Listening to Music Through Hearing Aids

The "Music" Program

Recently I've noticed that the professional and trade journals are publishing more articles relating to listening to music through hearing aids and cochlear implants, rather than focusing on just speech. Without minimizing the overarching importance of speech communication, apparently this change reflects a growing appreciation of the importance that music plays in many of our lives. Indeed, for some people, being able to hear music well may be as important as speech communication.

The unique factors related to listening to music through a cochlear implant were discussed in an earlier article; in this one, I'd like to focus exclusively on hearing aid users. Although the specific adaptations and needs of musical performers will not be discussed in this article, their requirements deserve special attention and are a topic in its own right. Any hearing aid feature applicable to non-musician listeners would also apply to them.

Sound Ranges Differ for Speech and Music

What comes up time and again is the fact that traditional hearing aids were designed with the goal of optimally responding to the acoustic characteristics of a speech signal, not music. There are important consequences emanating from this design requirement. The acoustic characteristics of music are quite different from speech, and a hearing aid that works well for speech perception may not be appropriate when listening to music.

For example, the range between the softest sounds of speech (the voiceless /th/) and the loudest (the vowel /aw/) is about 30-35 dB, while even the loudest

Would someone be able to enjoy music more if a hearing aid included such a music program?

Judging from the literature, it is likely that people with mild and moderate hearing losses should be able to hear the difference. ...Now that the literature has "discovered" the fact that hearing aid users enjoy listening to music, perhaps we'll see more projects on this topic.

speech signal rarely exceeds 85-90 dB. The current generation of digital hearing aids is designed to efficiently process this range of speech inputs.

However, in music, the range between the softest and loudest sounds is in the order of 100 dB, with the most intense elements (such as with brass instruments) measuring as high as 120 dB. The implication of these acoustic differences is that while typical hearing aid users may be able to comprehend speech quite well if they can hear 30-35 dB of the signal across a wide range of frequencies, much more of a range is required when listening to music. .

In order for someone to fully hear and appreciate all the components in a musical selection, the hearing aid must be designed to deal with a dynamic range of inputs in the order of 100 dB, from about 20 dB to 120 dB. Moreover, unlike hearing aids designed to maximize speech perception by emphasizing the higher frequencies, in music it is the lower frequencies that are the more important.

Further, the hearing aid must be able to amplify the lower frequencies without exceeding the capacity of the analog-to-digital (A/D) converter found in all digital hearing aids. (This is the circuit that converts acoustic inputs to a digital format.) These A/D converters were designed to process

speech signals and to do it without, or with minimal, distortion. While the first generations of digital hearing aids were not overly successful at this task, current models are able to manage the input range of speech very well. Many, however, are still not designed to deal with the range and intensity of inputs found in typical musical selections.

When confronted with musical selections, hearing aids with less than a 16 bit A/D converter may produce high levels of harmonic distortion that can affect the overall quality of the listening experience.

Hearing Aids Tested for Distortion

Recently, Dr. Marshall Chasin, of the Musician's Clinics of Canada, demonstrated major differences in harmonic distortion with five different hearing aids after they were exposed to sound inputs at 90 and 100 dB. At the 100 dB input level (typical for music), the harmonic distortion of three of these five aids exceeded 50 percent (a horrendous figure!).

Distortion levels were significantly less at the 90 dB input level. According to Dr. Chasin, all five aids, including the three that distorted quite badly at the high input level, "did quite well" in regards to speech perception, for which typical input levels would be 90 dB or less.

This is an important finding; it shows that a hearing aid's performance in regard to speech perception does not predict its ability to process typical musical selections. The converse, however, may well be true, at least for people with mild or moderate hearing losses: hearing aids that do best with music may also be

continued on page 28

Mark Ross Suggests...

Much more information about listening to music through hearing aids is available on the Internet.

For performers, the organization Association of Adult Musicians with Hearing Loss" (AAMHL.org) is an excellent resource.

Hearing Education and Awareness for Rockers (hearnet.com) seems primarily aimed at the younger set and includes suggestions on how they can preserve their hearing while playing and listening to music.

The Musicians' Clinics of Canada (musiciansclinics.com) is chock full of relevant information on this topic, much of which I depended upon while composing this article. I am particularly indebted to Dr. Marshall Chasin, Director of Auditory Research for his patient and informative response to all of my queries.

The Music Program

continued from page 27

able to deliver the best quality speech signals. And hearing aids that do well with music are those with wide frequency ranges and the capacity to process high input levels without distortion. A "Hi-Fi" system in other words—nothing new here!

Key Factors That Determine the Quality of Music

In the same issue of the *Hearing Review* (February 2009) in which the Chasin article appeared, Dr. Mead Killion examined the relationship between speech perception and the judged quality of music, for both normal hearing and hard of hearing people, as heard through hearing aids. Using a mannequin of a human head, he recorded various musical selections and a speech perception test through seven different digital hearing aids, an "open-ear" condition (no aid), as well as with the "Digi-K" (a hearing aid circuit that he developed).

He then played these recordings back to both normal hearing and hard of hearing listeners, and asked them to judge the fidelity (0 to 100 percent fidelity) of the musical selection. How good, in other words, did the music sound to them? The results show that the fidelity ratings varied considerably for the seven different aids, with the highest scores obtained in the "open-ear" condition and with the Digi-K. The important conclusion of this research is that both groups (normal hearing and hard of hearing) rated the fidelity of all the aids similarly; hearing aids that sounded best and worst for the normal hearing listeners were rated similarly by the hard of hearing subjects. Evidently, the key factor was the quality of the reproduction through the hearing aid, and not whether the person listening had a hearing loss or had normal hearing.

In another component of the same study, Dr. Killion compared the speech perception scores in noise obtained by 26 subjects with hearing

loss with these seven different digital aids to the fidelity ratings that normal hearing listeners gave to the aids. He found an orderly relationship between the fidelity ratings given to the various hearing aids by the normal hearing listeners and the ability of the users with hearing loss to understand speech in noise.

The aids judged to reproduce music with the highest fidelity were also the ones with which hearing aid users understood speech best.

This is a point worth repeating: Dr. Killion provides evidence for the assertion that hearing aids that best reproduce musical selections would also be the ones with which the highest speech perception scores could be obtained.

As indicated earlier, this requires a hearing aid that can respond to a large dynamic input range without distortion, as well as reproduce a wide acoustic frequency range (up to 16,000 kHz is often noted as the ideal, but this is hardly ever, if ever, realized in the real ear). We should keep in mind, however, that all the subjects involved in the above studies had mild or moderate hearing losses (who also happen to be the majority of hearing aid and potential hearing aid users).

We don't know how applicable these results would be for people with severe or profound hearing losses; their amplification needs may be considerably different from those individuals with less severe hearing losses.

The Music Program in a Hearing Aid

Hearing aid manufacturers are well aware of the acoustical differences between speech and music, and the different processing strategies that may be necessary in order for the aid to respond appropriately to either type of input. Some hearing aids with multiple memories devote one of them to a special "music" program. This can be selected automatically by the hearing aid based on the nature of the acoustical environment, or chosen deliberately by the hearing aid user

when listening to music.

While the specific acoustical modifications that different manufacturers include will differ, the recent literature suggests a few that should definitely be considered (in addition to the capacity to efficiently process a wide dynamic input range).

In music, as already mentioned, the low frequencies take on a significance not found when listening to speech. Consider, for example, that in an 88 key piano, 63 of the notes (72 percent) fall below 1,000 Hz. It takes a soprano to match that fundamental pitch.

For maximizing speech perception, on the other hand, it is the frequencies above 1,000 Hz that are most important. In an audiogram, however, the lowest frequency measured is usually 250 Hz, while the frequency range amplified by hearing aids usually begins at about 300 or 400 Hz. In music one can find fundamental pitches extending down to 82 Hz (a guitar), and even lower for other instruments. Thus in ordinary circumstances there is a mismatch between the audiogram, the frequency range of hearing aids, and many of the important pitches in a musical selection.

There are, for example, as many distinct notes on a piano between 100 and 200 Hz (12 of them) as there are between 1,000 and 2,000 Hz. If, therefore, we expect hearing aid users to fully enjoy music, they must be able to hear the lower part of the frequency range as much as possible.

Thus, when somebody switches to a "music" program, it seems obvious that this should include an extension of the low frequency range of the hearing aid. This is not to suggest that the higher frequencies can be ignored, since it is in this higher frequency region that much of the energy of stringed instruments falls, as well as the harmonics of the lower pitch ones; what it does suggest is that the lower frequencies require an explicit focus.

It has also been suggested that, in contrast to what may be best for speech perception, when listening

to music just one channel of amplification may be best (at least for people with mild and moderate hearing losses). While in order to optimize speech perception, it may be advantageous to deliver two or more channels of amplification (each one adjusted somewhat separately), the situation is different with music.

Unlike speech, to fully appreciate musical selections, it is necessary to preserve the original intensity balance between the lower and the higher frequencies. If a hearing aid reproduces too many, or too few, low or high frequencies this balance will be distorted. The music has to sound as it was performed, or as close to that as possible. A single channel instrument will help preserve this balance. If in a multi-channel hearing aid it is not possible to provide just a single channel, then each individual channel should be adjusted alike so that the hearing aid functions "as if" it were a single channel instrument.

The aids judged to reproduce music with the highest fidelity were also the ones with which hearing aid users understood speech best.

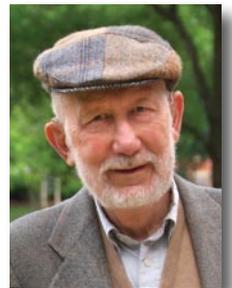
Finally, it has been recommended that, if possible, both the feedback and noise reduction programs be disabled when the aid is switched to a music program. Both of these features have been found very helpful in listening to speech: in one case permitting a higher degree of amplification before acoustic squealing occurs, and in the other case making it easier to hear in noise by reducing the gain in some frequency bands. However, these features may not be desirable when listening to music, since the original acoustical input may be unpredictably modified. A feedback circuit could attempt to cancel some desirable musical components (like narrow-band harmonics), simply because they "sound like" feedback to the sensor.

In addition, with short-duration sounds, the hearing aid-created cancellation signal could actually become audible. The same logic applies to noise reduction systems; the program may classify some component of the input as "noise" and modify it in an unpredictable and, likely, undesirable fashion.

Is a Music Program for You?

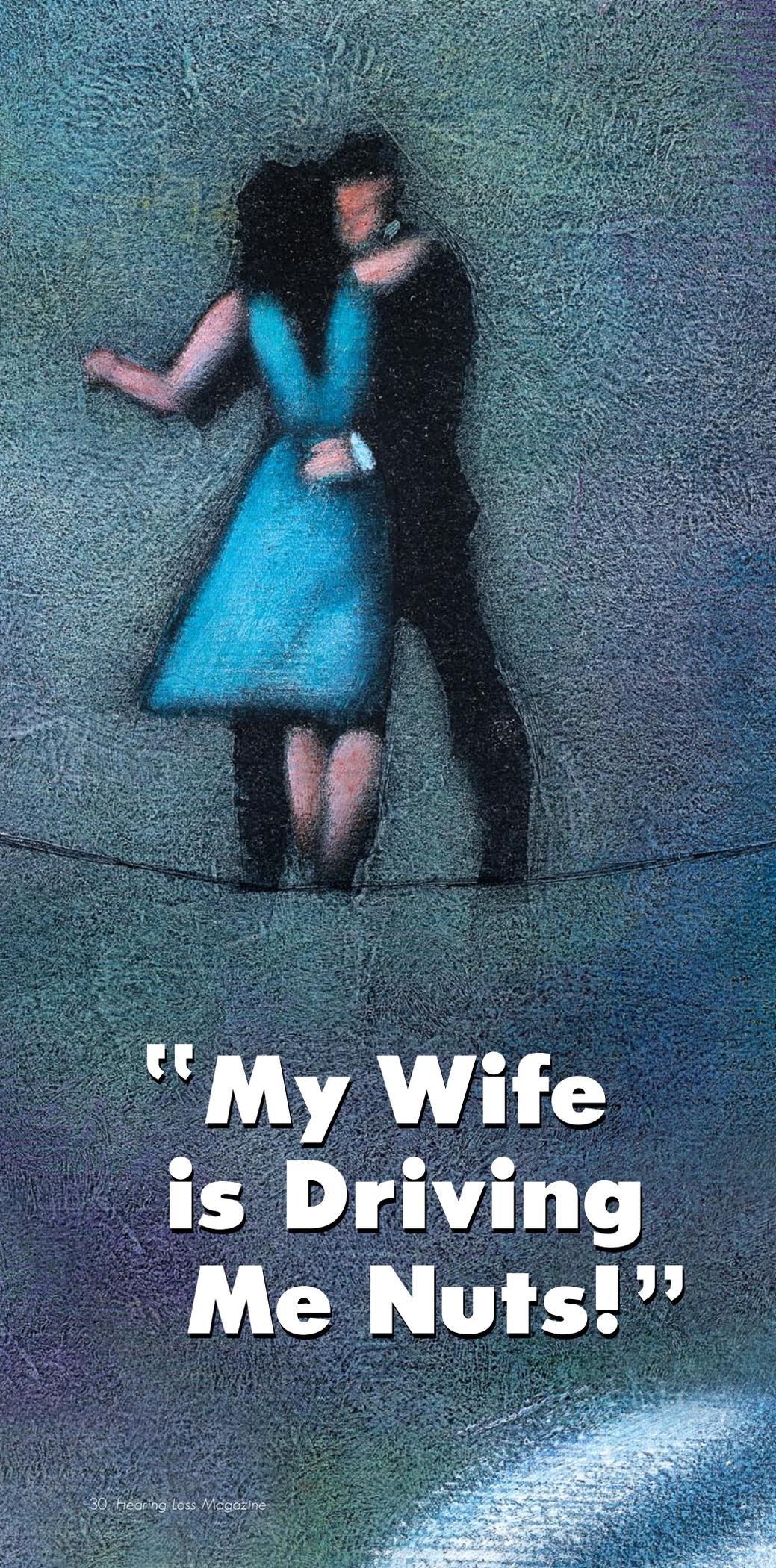
Would someone be able to enjoy music more if a hearing aid included such a music program? Judging from the literature, it is likely that people with mild and moderate hearing losses should be able to hear the difference. I don't know how this would apply to people with severe and profound hearing losses, but as best as I can judge, they might also find such a program somewhat helpful. At least it is worth a try. Unfortunately, we do not have much research (other than the articles by Dr. Mead Killion) that has investigated the fidelity of hearing aids in reproducing music. Now that the literature has "discovered" the fact that hearing aid users enjoy listening to music, perhaps we'll see more projects on this topic. ■■■■

Mark Ross, Ph.D., is an audiologist and associate at the Rehabilitation Engineering Research Center (RERC) at Gallaudet University. He was awarded the HLAA Lifetime Achievement Award in June 2008. He and his wife, Helen, live in Storrs, Connecticut. To find more Dr. Ross articles on technology for consumers, go to: www.hearingresearch.org.



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By Michael A. Harvey

Dr. Harvey writes for *Hearing Loss Magazine* and uses situations brought to him in his private counseling practice, e-mails, and his workshops and seminars. He specializes in behavioral health issues pertaining to people with hearing loss. The names and cities are fictitious, but the situation may sound familiar.

Dear Dr. Harvey,

My wife has been wonderful since I lost my hearing. She uses good communication skills, ordered visual doorbells and alarms in our home, and is sensitive to when I can't understand what people are saying. But lately she's driving me nuts!

She's always doing things for me. She has taken it upon herself to tell people that I am hard of hearing and habitually reminds them to talk slowly and clearly. She makes telephone calls for me whether or not I need it, and she always makes sure she's the one to talk with salespeople when we go shopping. She's treating me like I'm five years old! This recently came to a head when she insisted on coming with me to my hearing appointment and told the doctor how I feel. I would really appreciate any suggestions.

Losing my mind,
Tulsa, Oklahoma

Dear "Losing my mind,"

I often hear variations of your marital crisis, and your reference to losing your mind obviously speaks to your frustration. In addition, your phrase "losing my mind" may also be a metaphor for your sense of self, including your experience of self-competency, autonomy and worth. You should hold on to your mind as tightly as you

**“My Wife
is Driving
Me Nuts!”**

can so it doesn't get lost or taken away from you!

Although your wife's attempts to be helpful are undoubtedly motivated by her love and compassion, in a metaphorical sense, she is taking your mind away from you while, at the same time, you are giving it to her.

Love doesn't have to be smothering or infantilizing. In addition, your wife's behaviors are probably emotionally depleting to her, as constant hyper-attention to sparing you from challenges or anxieties would inevitably usurp her efforts to take care of her own needs. And to top it off, mental health professionals would correctly deem her as being "co-dependent": an entrenched pattern or "rut" whereby her self-worth is necessarily dependent on how you're coping with hearing loss.

It is important to appreciate and understand the ways that your hearing loss is emotionally affecting your wife. It is understandable that she would do almost anything to take away the pain of her beloved partner. I'll never forget the words of one woman—an interpreter—who had been married to a deaf man:

"Even as the Americans with Disabilities Act began to take effect, I watched my husband get fired for requesting sign language interpreters. The discrimination lawsuit my husband filed dragged on for three years. I watched him change from an empowered Deaf man to a bitter, angry person consumed by the inequities of oppression. I watched the results of his unemployment take root and fester in our relationship, the insidiousness and subversiveness with which it occurred was like a cancer—spreading with every rejection letter he received, and with every interview that failed to result in a position.

"It also wasn't easy for me. I began to withdraw from hearing society outside of work, and soon I realized that the only people with whom I interacted were Deaf people, interpreters, or other friends that could sign. I hadn't seen a movie in a theater for years because first run movies

weren't shown with captions at that time. I was starting to hate who I was."

I would advise you to set aside some time and space to ask your wife how your hearing loss affects her and to ensure that she feels supported in voicing her own struggles, even though she is not the one who has the disability per se. It is certainly apparent that, in your words, she "has been wonderful," but that quality can, and often does, co-exist with anxiety, fear, helplessness, etc. And a common way of coping with these feelings is to become overly helpful to one's spouse. The more your wife focuses on helping you, the less she is besieged by feelings that threaten to overwhelm her.

Important point: Your wife is half the problem (and solution), but *you are the other half*. Nobody, including your wife, has the ability to "take your mind" without you simultaneously offering it and even giving it to her. Don't offer it! Although you may be hesitant to ask her to modify her attempts to help for fear of hurting her feelings, you can say something like "I appreciate your wanting to [fill in the blank] and I know you offer out of love, but that isn't helpful to me. What I would appreciate is..."

It would be important to explicitly clarify and, if necessary, "negotiate" specific ways that your wife could be helpful and also ways that you can ask her for such help. Although the specifics vary, all marriages have so-called "policies and procedures." (A relevant quotation: "Marriage is not just spiritual communion; it is also remembering who takes out the trash.") But these policies/procedures are often implicit—unspoken—and therefore set the stage for misunderstanding, conflict, resentment and then for both people to in effect "lose their minds."

Perhaps you and your wife can clarify and negotiate how and under what conditions it would be helpful for her to step in and help clarify communications for you. One hard of hearing man, for example, requested that his wife "interpret in social gatherings but never with my mother."

Gender Differences

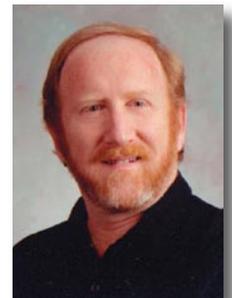
It is interesting to note possible gender differences in coping with hearing loss. A study conducted by Lisa Getty reported that when husbands have the hearing loss, their wives generally tend to be supportive, nurturing, and protective of their husbands in social settings, and quick to take charge.

However, when wives have the hearing loss, the situation tends to be quite different in that husbands usually are less supportive. Getty found that younger wives with hearing loss, especially, seemed to have husbands that are quick to stigmatize their use of hearing aids. If the two are going out for an evening together, the husband may say, "Oh, you won't wear those things, will you?"

Clearly, your hearing loss represents a crisis in your marriage, but I don't mean that in a negative way. When written in Chinese the word "crisis" is composed of two characters: one represents danger, and the other represents opportunity. The present task for you and your wife is to avoid the danger and nurture the opportunity. ■■■

Michael A. Harvey, Ph.D., A.B.P.P., provides training and consultation on hearing loss, vicarious trauma, and mental health issues. As a clinical psychologist, he has a private practice in Fram-

ingham, Massachusetts, and is a consultant faculty at Pennsylvania College of Optometry, School of Audiology (Salus University), where he teaches online courses relating to the psychosocial aspects of hearing loss. He is a regular contributor to Hearing Loss Magazine and his books include Listen with the Heart: Relationships and Hearing Loss, The Odyssey of Hearing Loss: Tales of Triumph, Psychotherapy with Deaf and Hard of Hearing Persons: A Systemic Model, and co-edited the book titled Culturally Affirmative Psychotherapy with Deaf Persons.





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Share your good news. If you have news about what is happening in chapters or state organizations, send 400 or less words and JPG photos (300 dpi) to Editor Barbara Kelley at bkelly@hearingloss.org.

Family/Couple Membership

When you join HLAA, you have an option for a Family/Couple membership. The price is \$45 per year and gives two votes in the national elections for the Board of Trustees. Some spouses are active in chapters and may want to be able to have their vote count. See the card inside this issue for how to join.

New Yorkers Look Forward to Captioned Films Under the Stars

The Manhattan Chapter formed an advocacy committee a few months ago with a goal to achieve greater communication access and services for people with hearing loss.

Member Toni Iacolucci says, "We are a small group of people with little advocacy experience, but we have a passion about the issues, including captioning and noise awareness. We are fortunate to have two advisors who are long-time HLAA members and advocates—Ruth Bernstein and Joe Gordon. Forming a committee and getting good advice has worked well. I don't think people need lots of experience to be effective advocates, but you do need 'go-to' people who can advise on important issues, especially in regard to the Americans with Disabilities Act."

Toni went on to say that New York City has several outdoor summer film festivals—none of which have been captioned, until now. Thanks to the Manhattan Chapter advocacy committee, two sites will show captioned films this summer:

Summer on the Hudson, Movies Under the Stars

Wednesdays from July 8 to August 12
Thanks to the Riverside Park South and the City of New York Department of Parks and Recreation who were the first to commit to showing movies with captions. Go to: http://gonyc.about.com/od/summer/a/summer_hudson.htm

7th Annual Central Park Film Festival
Five nights in a row, August 18-22
Thanks to the Central Park Conservancy. Go to http://gonyc.about.com/od/summer/a/central_park_ff.htm

Lessons Learned

Toni Iacolucci says she and the committee learned some great lessons in watching this summer film festival issue unfold. She shares some thoughts here:

Be Passionate: It helps to feel strongly about a particular issue. If it's meaningful to you and you express this to people you approach, it will become more meaningful to them.

It is rewarding for both sides to work on issues that have local impact. It's great to be able to see and enjoy the fruits of our labors.

Ask: As people with hearing loss, we're so used to not having access that sometimes we don't even think to ask for it. I walked by summer film festivals on many occasions and just accepted that I couldn't attend because there were no captions. One particular summer evening, my husband and I walked by a festival close to home and felt sad we couldn't stay and watch with our neighbors. It was that sadness that triggered my desire to pursue communication access at festivals.

Educate: I think people with hearing loss often assume everyone is aware of the issues and challenges we face. That is not true. I find people generally cooperative and they end up feeling good about the fact that they've enabled greater access once they understand how lack of it affects our lives.

Have a Positive Approach: I feel this is the key to effective advocacy. When I start with an upbeat tone and if I am understanding of someone's discomfort about talking with me either in person or on the phone, and give them time to digest and think about the issue, and be willing to compromise, then we'll have a greater chance of accomplishing our goals. 

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Neither Here, Nor There

The author writes about living between two worlds.

Robin-Marlena Itzler is an HLA member from Cypress, California, and is president of a non-profit humane organization. She and her husband founded Royal Care Pet Sitting, a leading sitting service in North Orange County/Greater Long Beach, California. Recognized as an expert in the field, she writes a regular column for the premier pet sitting organization on how to market the business and also conducts seminars on how to have a successful pet sitting career. Robin-Marlena and her husband share their home with their beloved dogs.

People have a tendency to take the unfamiliar and classify as one group contrary to the group itself. For example, Hispanics supposedly encompass every Spanish-speaking person from Peru to Cuba to Mexico to Spain. But when you talk to citizens from these countries, they see themselves as totally distinct from their Spanish-speaking equivalent in other parts of the world.

This happens in the hearing loss community, too. The hearing public interchanges being totally deaf and hard of hearing when they are two distinct categorizations. We're such a complex group that even the term "hearing loss" doesn't convey who we are. The deaf infant is the polar opposite of the elder whose hearing has diminished with age. The child diagnosed at age six (me) with nerve deafness is dichotomous to the middle-aged person losing hearing from having worked in construction, surrounded by obscene noise levels.

But somehow we're all lumped into this one group and we're supposed to have identical needs from our family, friends, coworkers, bosses and government.

Due to inherited progressive nerve deafness I've been wearing behind-the-ear hearing aids since my mid-20s, having held out a few years too long because I refused to admit the need for aids. Now I'm in my mid-50s and can hear very little sound without the aids and mostly rely on the combination of sound and lip-reading.

I don't like the term "hearing-impaired" and radically detest the phrase hard of hearing. Are people with sight problems referred to as hard-of-sight? I'm NOT impaired or hard of anything—this is just who I am!

Ah, but the grass is always greener on the other side—and it's human nature to assume that what you don't have would have been better for you. With progressive hearing loss, I've spent much of my adult life wishing I had been born deaf. Oh, I am sure that many deaf people would give anything to put aids into their ears to hear what I can still capture.

But the reason I've felt this way is that by having some hearing I am constantly tossed from the hearing to the deaf world and back again. It's like being in purgatory. Hearing people see the aids and erroneously assume they are like glasses, giving me 20/20 hearing. And when I miss conversation, they assume I have selective hearing. Deaf people, on the other hand (pun intended), rapidly wave their fingers in a linguistic dance that is a galaxy far, far away.

I am tormented by feelings that I don't belong anywhere. Those hearing aids are part of me at work but when my lunch break arrives, they are turned off during an exercise walk, happily enveloping me in a blanket of silence that also affords a sojourn from lip-reading.

Once home, I take them out. Closed captioning and e-mail allow me to "hear." Most evenings I wear one old aid to have an easier time conversing with my normal hearing husband.

Yet, it's rare for me to have a pity-party. Instead I am like millions of other people with their own unique challenges (financial, personal, physical—whatever they may be) who trudge through life trying to make lemonade out of lemons. Until you read this article you never heard of me because my name doesn't appear on any marquee or award although I have a "best wife" statue in my kitchen.

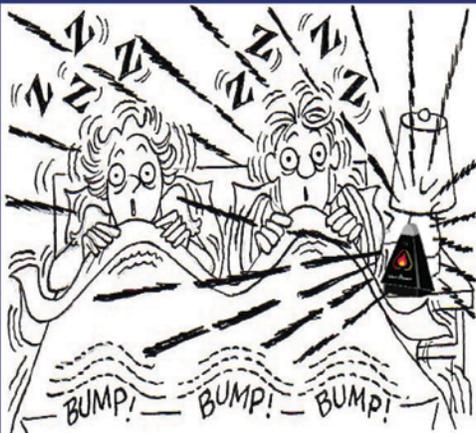
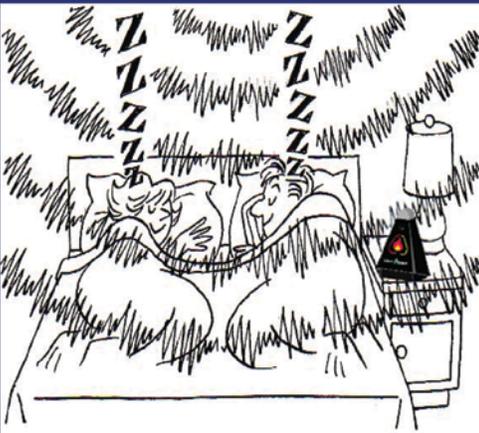
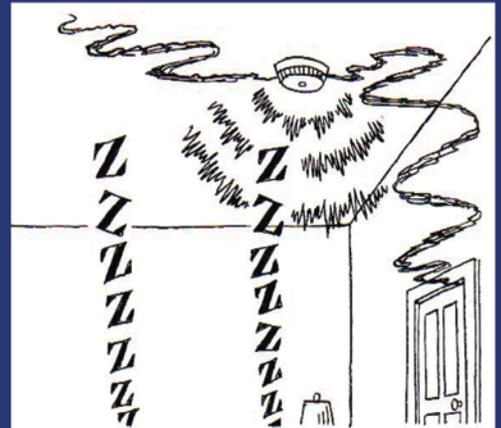
Still at the end of the day, I am besieged by feelings that I don't belong in either the hearing or deaf world. Sometimes it's all topsy-turvy to me. For decades the hearing loss community demanded technological advances to make even the most powerful hearing aids so small that others wouldn't notice them. Yet now our hearing friends walk around with a large Bluetooth® sticking out of one ear. Maybe I should have aids designed like a blue tooth so no one will notice!

The synopsis of my life is that there are days when I confront numerous uphill challenges and am amazed with my success. Other days it's the drone of combining nothing and everything as most hearing people lump me into a one-size-fits-all category.

If you'd like to read more about my experiences, I'll write again. But for now, I'm going to have a cool glass of lemonade. ☺☺☺

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