

By Bill Barkeley



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Bill Barkeley

NO BARRIERS

I was born a normal healthy baby boy in 1962. I am the youngest of five children who grew up in Grand Rapids, Michigan. I lost 85 percent of my hearing in the low tones and 100 percent of the high tones before the age of five.

As luck would have it, I was born five doors down from one of the first oral deaf kindergarten programs in the country—Shawnee Park Elementary. I was fitted with one hearing aid, learned lip-reading and underwent extensive speech therapy.

In the 1960s, there was extensive debate on the future of deaf education and the options available to parents and children. My parents chose to mainstream me into a Catholic parochial school in the first grade. From there, I progressed through grade, middle and high schools in Grand Rapids, Michigan and Palos Verdes Estates, California.

At the age of 18, I decided that vanity was no longer an option. I needed to embrace two hearing aids to survive the rigors of a college education and successfully deal with a severe-to-profound hearing loss. It was a huge advance forward for me in terms of performance, because I managed to make it all the way to the Dean's List. I often joke that this was the year I went from mono to stereo sound and it made a huge difference!

I excelled at the University of Southern California in an education era that did not offer many resources to people with hearing loss in terms of personal aides, note-takers or technology tools. I just simply went to class and put the pieces together to prepare for and pass my tests. I had no idea what was out there and available to make my academic life easier.

I found out that not only was I deaf but I had been slowly going blind all my life....

I was diagnosed with Usher Syndrome Type II. I was one of 15,000 people in the United States and 100,000 in the world with this leading cause of deaf-blindness.

To put things in perspective, in 1984, my senior year in college, Steve Jobs introduced a revolutionary new technology marvel called the personal computer. Little did any of us know how much our world and lives were to change—disabled or not—with this technology platform and a future innovation to come called the Internet.

Upon graduation from college, I was one of 12 people selected from a pool of 3,000 candidates for a position with a Fortune 500 company. With God's grace, family, friends and community, I found my way forward after college as a young, deaf professional in Seattle with a promising future in sales and marketing.

Shortly thereafter, I picked up a renewed relationship with my former high school classmate and family friend as she was recovering from an almost fatal car accident in Washington, D.C. We started dating and before most of our friends and family even knew we were dating, we were married within the year. Mary Beth has been my rock and inspiration these last 24 years!

In 1987, Mary Beth and I were married and moved to the Bay Area to start a promising future for both of us. In a very short time, we were a dual income couple working for two global corporations, bought our first house, and had our first son, John.

Something Went Horribly Wrong

In fall 1987, the world as we knew it changed—slowly at first—then it was completely turned upside down. I was 27 and was driving 40,000 miles a year as a rising sales executive. I had a series of three car accidents—all at sunset, all left hand turns—and where I broad-sided other cars.

My reaction was “the first accident was other guy's problem, the second accident was that I needed to be more cautious.” After the third accident, I knew something was horribly wrong. That “horribly wrong” took a year to figure out as I went from Stanford to the University of Michigan and Harvard to find out what was happening.

I found out that not only was I deaf but I had been slowly going blind all my life. I sat there in a doctor's office unraveling the mystery of an insidious disease that robs people of both their vision and hearing progressively over time. There were no treatments or cures. I was diagnosed with Usher Syndrome Type II. I was one of 15,000 people in the United States and 100,000 in the world with this leading cause of deaf-blindness.

This really set me, and us, back as we both emotionally and intellectually tried to come to terms with what my future looked like without hearing and vision. It was not a pretty prospect, yet Mary Beth and I chose to fight back and learn what we could about the disease. The Internet and genetic testing were in their infancy and were just two innovations that would help us learn, cope and share our journey with family, friends, community and the rest of the world these past 24 years.

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Other Than Sight and Sound, Something Was Missing

By 2007, I worked my way up to being a director for sales and marketing of a Fortune 500 company. I had 30 employees across the United States, Canada and Mexico. My family grew to three sons and we were very busy.

Yet, something was still missing.

I needed a challenge and a vision to help me take on the next phase of my life. I decided to climb Mount Kilimanjaro in Africa to get the word out about how hearing aids, FM systems and Bluetooth technology were changing the ways that people with hearing loss live, work and play.

It changed my life.

I retired from my 25-year career. I became a deaf-blind adventurer and storyteller, traveling the globe while sharing a message of inspiration, aspiration, hope and faith for those with hearing and vision loss. I have experienced the power of the human spirit and God has opened up many doors for me to help others.

I found out that I am not so special. Anyone can do what I am doing. I see amazing, inspiring and determined people wherever I travel around the world. My projects to get the word out on hearing loss are not about me. They are about people being encouraged to take on their own challenges and getting others to help them get to where they want to go in life one step at a time. By taking on the mountains in our lives, literally and figuratively, it is possible for anyone, with a disability or not, to seek a "Life Without Limits." 

Walk Your Own Path, a film by Josh Levine, documented Barkeley's climb of Mount Kilimanjaro. The climb was covered in the July 2008 edition of Outside Magazine. Bill is active in community service. He is past president of the Association for the Blind and Visually Impaired (ABVI). He is on the executive committee of the Hearing Loss Association of America (Grand Rapids chapter). Bill can be reached via e-mail at billmessage@att.net.

Creating a Life Without Limits

From the Mount Kilimanjaro experience came the inspiration to give back to others as so many friends, family members and mentors have done for me over the years. I decided to launch the Hear The World Expedition to mentor the next generation of young deaf people. The expeditions are about taking responsibility for oneself, your disability and helping others around the globe.

In July 2010, we took a group of awesome kids, both with and without hearing loss, to the Peruvian Amazon on the first Hear The World Expedition. It was covered in social media and traditional media around the globe, and this next generation of kids with hearing loss is teaching us what "no barriers" leadership is about.

1. Explore with Bill

We are looking for more kids to join us on the second Hear The World Expedition with Global Explorers. The Grand Canyon Rim to River Expedition in partnership with the National Park Service will help us shatter expectations and move the conversation forward on hearing loss and its impact on 16 percent of the world's population. Applications start January 3, 2011. Visit www.globalexplorers.org.

2. Travel and Listen to Bill

There is an incredible opportunity for adults, parents, families and kids to join us in South Africa next July for the World Deaf Congress 2011, sponsored by the United Nations. I will be there to share a message of "Life Without Limits" using assistive technologies such as hearing aids and FM systems for hearing loss. I'd love to have a strong HLAA presence in one of the most remarkable countries in the world in South Africa. www.wfd2011.com

3. Adventure with Bill

I am on the board of directors of No Barriers USA (www.nobarriers.org), a powerful community of modern day pioneers who use the experience of nature to promote innovation, education and assistive technologies that create transformative life experiences and inspire people with challenges to live full and active lives.

Every couple of years, in a naturally beautiful and challenging setting, the international No Barriers Summit brings together adventurers and outdoor enthusiasts as well as scientists and innovators for an outdoor summit unlike any other. The No Barriers Summit combines hands-on clinics, product demonstrations, nature excursions, films, art and music, keynote addresses, leadership exercises and a scientific symposium. We feel there is no way to separate technologies from challenges and believe that inspiration and opportunity fuel achievement.

This Summit will give people who live with challenges the technologies and techniques needed to help them live more active lives. Not only is the Summit a multi-day event, but it is also multi-faceted, consisting of:

- Summit Symposiums
- Life Experience Clinics
- Innovation Village
- Inspiring Speakers and Films
- Trailblazer Networking

Each day is about sharing, partnership, inspiration, discovery, exploration and accomplishment. Here, you'll meet people like you—people who let themselves dream big and are invested in creating a bold vision for tomorrow. No Barriers Summits replace our perceptions about disability and personal challenges with a renewed belief in what is possible and what will be in the future.

The No Barriers USA 2011 Festival runs from June 28 - July 2, 2011, in Winter Park, Colorado. Visit www.nobarriersusa.org/summits/2011/. 

South Africa... The Trip of a Lifetime!

By Bill Barkeley

South Africa wants to be a global model in promoting universal access for people with all disabilities. In the post-apartheid world, they have a deep respect for those who are under-privileged and under-represented in their country.

Last year, I was invited to South Africa to share my travel experiences as a person with vision and hearing loss. My input will be used to plan the XVI World Congress of the World Federation of the Deaf to be held this July in Durban, South Africa, where I will participate on a panel of international speakers. I will also participate in the Disabled Peoples International 8th World Assembly in Durban, in October 2011. We experienced incredible highlights of life in South Africa.

My wife, MaryBeth, and I traveled for 10 days with Jennae Tachea, who has a hearing loss and runs Access2Africa (www.access2africasafaris.com). She is a specialist tour operator for accessible and inclusive travel. She lives in the North Coast of South Africa just outside of Durban and she is currently promoting safaris for people with hearing loss. Her husband JJ was paralyzed in a swimming accident and is a rising talent in the art world with amazing wildlife pictures that he paints with his mouth. Two incredible and inspiring people that took us into their hands and hearts as they showed the best that South Africa has to offer.

Two incredible highlights were the Elephant Interaction Centre and the Emdoneni Lodge Cheetah Centre. The Elephant Interaction Centre is where people with disabilities can interact directly with a herd of elephants consisting of a mother, father and baby. The education and feeding activities were designed so that people can touch, see, feel and feed the elephants directly. It is hard to describe the feeling of walking behind an elephant's trunk and tusks and sticking one's arm directly into a cavernous mouth and tongue of one of the world's largest animals. It was beauty, danger and emotion wrapped in one big package of adventure.

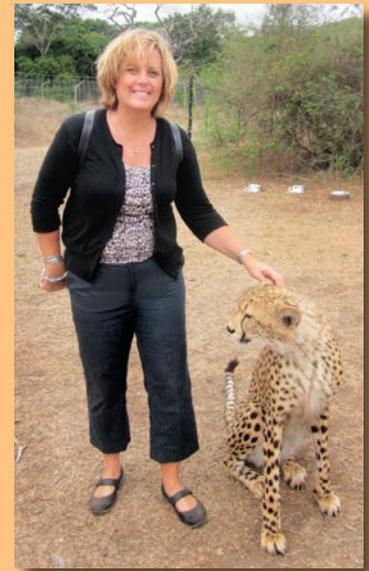
The Emdoneni Lodge Cheetah is a place where one can actually see and pet cheetahs. These amazing animals are fast on land and have a very unnerving cat-like sound. They call it purring—I call it panting on steroids. As my wife, Jennae, and I were in a pen with two large cheetahs and the park ranger, we could feel the vibrations of the cheetahs breath as we stroked their heads. They were tame but are capable of wielding strong power. One cat softly stroked his paw at our guide Jennae and it hit her shirt and tore it across her mid-section. What is a good trip without a tale that will grow as the years go by?! This direct interaction for people of all disabilities is powerful—as they get a chance to interact with the world's most exotic animals.

Traveling By Car

South Africa will be launching another travel innovation at the World Deaf Congress. All visitors will be able to rent the world's first fully communication accessible travel system for your car as you travel.

Piet Human from Incar Travel had us use and test his new in-car travel system that people with and without disabilities can rent as they tour South Africa. This amazing device is the first of its kind in the world. Using Garmin GPS technology, a video player system and audio, the Incar Travel System takes you on a personal tour of South Africa landmarks, history and attractions triggered by your GPS location. Imagine driving down the highway and learning about the Zulu tribes that inhabited the area or where the next attraction is and what to expect once you get there. People with all types of disabilities and many languages will be able to use this system complete with captions and/or voice output.

We'd love to have as many Americans as we can come to South Africa this year. For more information on the World Congress, go to www.wfdeaf.org. For more information on the Disabled Peoples International World Assembly, go to www.dpi2011.co.zain. 



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By MaryBeth Barkeley

I have known Bill since the eleventh grade. He only wore one analog hearing aid at the time. When I began dating him, years after high school and college, I loved his ability to completely concentrate, provide wisdom and his undivided attention to me. I attribute a lot of these qualities and interpersonal skills to his compensation for his hearing loss. He would focus directly on my face and listen intently. I found this very flattering and we began to date after our long-standing friendship of many years. He was really just trying to read lips when I was talking, but I felt he gave me his undivided attention. I loved that about him.

Bill's hearing loss was never an issue. His attention to detail, body language and manners had become so acute—coupled with his charm—that he made up for any hearing loss he had back in our dating days. Everyone admired his friendly good nature, his intelligence, his active lifestyle, his candid sense of humor, and his adaptability to most people and situations. Little did we know how important those

batteries in my purse, to protect them from getting wet (never tip the canoe) and finish all pillow talk before the hearing aids come out. These “little radios” (his hearing aids), as Bill explained to curious children, could play songs like “Jingle Bells” if he pulled on them. He always said, “you are my ears and I will be your eyes,” because I was severely nearsighted. We assumed he had lost his hearing due to measles.

Before the diagnosis, Bill's hearing loss was just a part of who he was. He had been wearing hearing aids since he was five years old and was very comfortable with himself. If anything, it endeared people to him because he made it seem effortless and people wanted to be around this positive, upbeat guy. In his late teens, Bill wore one hearing aid and used to grow his hair in an 80s afro-look to hide the hearing aids. In college, he became more self-assured and decided to wear the two hearing aids. We were good friends through college but at different schools on opposite ends of the country. We had long phone calls to keep in touch, along with great letters. I considered him one of my dearest friends. I began my career in Washington, D.C., while Bill was in Seattle.

Our friendship was solid and we were brought to our hometown for various reasons. The romantic relationship turned to marriage within a year. Our jobs transferred us to San Francisco, where we began our journey together.

A Communication Pact

Hearing loss required me to speak clearly and express myself—not just expect him to pick up on the inflections in my voice and the innuendos. This game was not new to him and he had learned to overcompensate for not hearing. I noticed that he was sometimes bluffing his way through the conversations and failing to understand it completely. He would fill in the gaps but ask me questions about what he had heard afterwards. This was a new role for me to assist with communication. I learned early on to catch him saying “exactly” when in conversation. I knew he was listening intently but felt that was a safe response. It is a long-standing joke among our kids that if Dad says “exactly,” that means he really didn't hear everything.

Some situations are absolutely hysterical. People will scream because they know you can't hear. The most courteous thing people can do is ask

For Better or for Worse...

traits would become as we learned early in our new marriage what was ahead.

We were newlyweds living in San Francisco when Bill was first diagnosed with Usher Syndrome Type II, a form of Retinitis Pigmentosa. With this disease, hearing loss occurs in the first two decades of life and then the peripheral vision begins to diminish in the later decades. The news was devastating, especially since we had become new parents. Neither of us ever gave much thought to Bill's hearing loss or ways to handle it. We traveled, made new friends, and enjoyed spending time together. I learned to carry hearing aid

Communication is the most important element and the glue that binds the relationship and validates the other person. Being married for 24 years is a real feat no matter what the circumstances. I have to say that our circumstances, although seemingly challenging, have proved to bring us closer together in an effort to stay connected and active. We have witnessed the promises we made “for better or worse, in sickness and health, for richer and poorer.”

if they are speaking clearly and loudly enough and if there is anything they need to repeat to please let them know. Also, it is so considerate when a host asks where the best place to sit might be. A little effort helps the individual with hearing loss learn to advocate for themselves. Bill gradually became more comfortable with this role, but he is much more comfortable being “one of the guys” even if it means he misses out on some of the details. Our neighbors in California were an Australian couple and our friend, Wolf, had a huge mustache and mumbled very fast with his accent. Bill often would

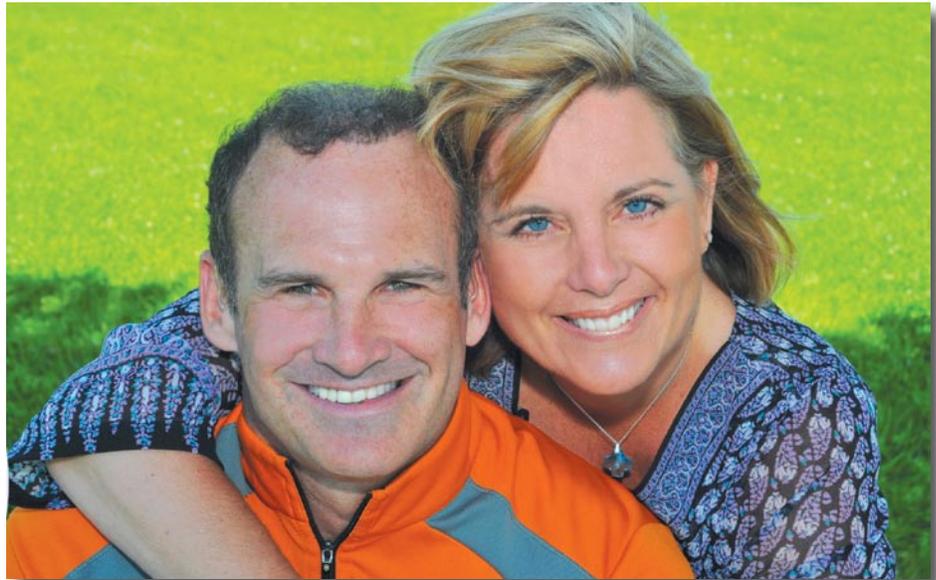
say, “Wolf, I can’t understand a damn thing you just said but I’m sure it’s not important anyway.” The crazy mustache made it impossible to read lips. They would laugh and Wolf would be more conscious of speaking clearly for Bill.

Our first son, John, was born at Stanford Hospital in 1989, the year of the big earthquake and the collapse of the Bay Bridge. Nine months later, Bill was diagnosed with a form of Retinitis Pigmentosa. He had gotten glasses a year prior and discovered that he had no peripheral vision. We took this news to Stanford, and they did not agree. We thought nothing of it and continued to focus on starting our own family.

Bill was having recurring minor car accidents, ripping off car mirrors, missing exits, tripping at work, walking into planters, etc. He had a strong feeling there was something amiss. The diagnosis was confirmed and we sought advice from around the country. This was difficult without the Internet, Google searches, Amazon, and instant responses from e-mail. I was shocked and devastated by the news and could barely function. Bill was comforting me and I realized I need to get a grip. I then became obsessed with finding information about this rare disease, which we later found out was called Usher Syndrome Type II. It is known as the leading cause of deaf-blindness in the world. I found my way to the Stanford Medical Library, made contact with the Foundation Fighting Blindness (FFB) and started a new journey.

Feeling more like a pioneer on this road, we met several families and individuals who were on this same path. This networking was invaluable to me. We learned to share, ask questions and encourage one another. It is certainly not a death sentence, so we decided to embrace it, be open about it, and share our experiences with others. We had to push each other at different times to open up and ask for help along the way.

Fortunately, the visual deterioration happens gradually so we were able to prepare for the loss. We learned that the disease was recessive-recessive and the chances of our kids getting it were slim to none. We were blessed with two



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Bill and MaryBeth Barkeley at HLAA Convention 2010 in Milwaukee

more sons after the diagnosis, Brian and Will. Both of these babies were born in Michigan because we had transferred back to my hometown. Bill decided to pursue his sales and marketing career through a Training and Management track to avoid relying on the automobile. The move came the year after the diagnosis, the baby and the major earthquake. It was a traumatic year; but we were proud new parents, and that helped distract and consume our pain.

We came through it all with youthful optimism and the support of family and friends. We value those relationships that provide unconditional love and support. We began to explore our rich Catholic church history because we were curious about God’s plan for our lives. We became more committed to involving our faith into our daily walk. In our kitchen are the words, “We Walk by Faith, and Not by Sight”—*Corinthians*. We are fortunate to have hearing aids and all the technological assistive devices that are available. But, nothing compares to Divine assistance through prayer and cooperation. We have been led down many interesting paths as our tour on this road continues to be one with our faith journey.

Relationships and Technology

Hearing loss does not take a backseat to vision loss. We recently heard a quote by Helen Keller when asked if

she thought losing her vision was worse than losing her hearing. She answered, “Vision loss cuts one off from things; hearing loss separates one from people.” The solution lies in relationships.

As Bill gradually slips into the non-sighted world, he relies more on assistive technology for independence but nothing compares to strong relationships and an interdependence that someone understands and will walk by his side. Other people assisting provide the greatest sense of security and well-being. Because I am Bill’s wife and best friend, I primarily fill that role on a continuing basis, but we are discovering that a spouse becomes more of a caregiver if this role takes over. This is relatively new for us because for the past 20 years we just needed a little assistance having had enough sight to navigate and hearing enhanced by digital hearing systems. But in recent days, it is clear more support is needed for Bill to get around as his condition progresses.

Staying physically active has helped both of us in different ways. Bill has always liked to run, ski, boat, golf and play hard. I have always encouraged this but with much trepidation, always worried that he was in some danger with his lack of hearing and sight. He has had problems with keeping his hearing aids from shorting out due to the moisture from sweating in a workout. He devised

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a system to wear a skull cap with strong wicking properties. I have tried to be his partner, but this is his time away and frankly, I like to talk and socialize on my workouts. Bill prefers the silence because it is more relaxing than trying to hear and respond. He has pursued other avenues, including tandem biking with a friend. They rode 175 miles this summer for Multiple Sclerosis Foundation. He skis out West with a vest (Blind Skier) and follows a guide who wears a vest (Blind Guide). As his vision loss progresses he may use the FM Microphone worn by the guide that will direct verbal cues to his hearing aids.

He Will Always Find a Way

That is what I have learned and come to trust about Bill. He has enjoyed many adventures and is using them to raise awareness for physically-challenged people. He is passionate about getting out and enjoying nature and adventure. It has always been a very empowering part of our life. When we are kayaking on Lake Michigan, we momentarily forget our challenges. He works to see that people have opportunities through adaptive sports groups. I prefer to exercise to stay active and be with friends to relieve stress and worry. Our kids have participated in athletics so we have spent many days on the bleachers watching, cheering, and assisting the coaches. These activities have provided entertainment and friendships with other parents. A hearing loss should not be an obstacle to getting out with people and being involved. Bill has found it may be a struggle at first but is worth the effort.

He has a Shake Awake alarm clock set to vibrate the bed in the morning. He has closed captioning on the TV, and has found a digital TV system that sends sound directly to his hearing aids. He discovered the Amazon Kindle to read or listen to books, then upgraded to an iPad, which he can read and listen to digitally (without a headset) directly to his hearing aids. The phone has improved with the Bluetooth technologies. We are grateful to live with all these advancements.

I still miss being able to whisper in a movie without him saying, "What?" so loud that the person in front of us gives us a dirty look. Conversing in the car can be challenging as well, especially if there are people in the back seat trying to talk. I have heard that autos can be looped, but Bill is resistant. This technology helps Bill hear at Mass on Sunday and various concerts and plays around town. I don't always have to say, "Honey, did you hear that?" Nothing is more annoying to him.

The irritations and frustrations that I feel because of his hearing and vision loss pale in comparison to the daily nuisances he faces in trying to navigate and hear what's going on around him. For many years he managed the North American sales force and traveled the country many times a month for work. He gave up the automobile about five years after he was diagnosed but still continued air travel and cabs to get around. I am supportive of his strategies for coping, but he does not want me to hover and fix them for him. I have learned to back off and respect his desire to manage these difficult tasks and look to assist when I can. There is a constant battle for balance between us.

Our sons, John 21, Brian 20 and Will 16, could fill your ears with hilarious stories of growing up with a hearing impaired parent. At parent-teacher conferences one year, the teacher met us and immediately said, "Now, I know why your son speaks so loudly" upon seeing Bill's hearing aids. Another babysitter said, "Your kids are so loud!"

If Bill had opted for sign language and Deaf culture our world would be much quieter. He relishes his time spent in complete silence without hearing aids. Every morning he gets up before anyone in the house and reads, prays and contemplates life. I know it is his most peaceful way to enter the noisy world. He loves to take his aids out at the end of a very busy day.

When the kids were infants, I got used to the late-night feedings and was envious of his ability to sleep through the night because he could not hear. I learned to send signals with a nudge or a jolt to wake him up to relieve me if it

was a challenging evening. When they were toddlers and woke before dawn they would jump on Bill, hand him his hearing aids and say "Daddy, put your ears in."

As they got a little older, I remember standing in line at a fast food restaurant and an interesting teenager was in front of us. They said, "Mommy, boys don't wearing earrings, they wear hearing aids." I broke out in laughter. These boys grew up thinking that hearing aids were no different than a pair of glasses. They are very sensitive to the special needs of those around them because of their father's condition.

We are still learning new steps to this dance, as Bill has recently retired from his career due to the progression of his condition and the demands of being a corporate executive.

He is focusing on advocacy for the hearing and visually impaired, and all the physically challenged. He found very few role models when he was diagnosed with Usher's and growing up with his hearing loss. It is important for him to let the general public know that there are many resources available and strong networks to help families. Much work can still be done to get hearing aids covered by insurance and help alleviate the stigma associated with wearing them. We plan to tackle some of these issues in our retirement and help those people who have been put in our path. We will continue to live loudly, work tirelessly and play vigorously and encourage those around us to join in our mission. ■■■■

MaryBeth Barkeley works part-time as the Community Service Representative for HomeInstead, a non-medical home healthcare company, in Grand Rapids, Michigan. She loves to entertain friends and family, and volunteers in her sons' schools and athletic endeavors. She enjoys freelance writing, traveling, skiing, golfing, summers at Lake Michigan, and walking with friends.



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