

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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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,

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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

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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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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

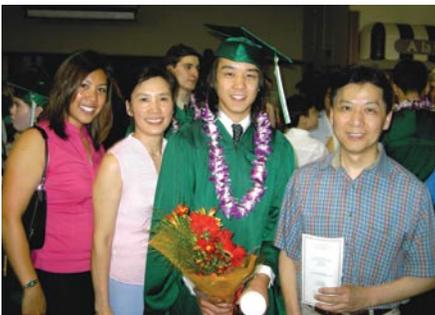


In 2007, in Washington, D.C., Jennifer spoke on behalf of the Hearing Aid Tax Credit Bill, of which Rep. Chris Van Hollen is a co-sponsor.

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.

