American Girl®
2020 Doll of the Year
Joss Kendrick Joins
the Walk4Hearing
I was born different. At birth, I had a very rare deformity with both of my ears called microtia and atresia. Here is the story of my journey.

Labeled Before I Had a Name
I was born in Cincinnati, Ohio, and lived in the West End community. I was the firstborn and the first grandchild in my entire family—as well as the first baby born with two non-developed ears. My journey with bilateral microtia and atresia began in December 1982, when I entered this world and was immediately labeled “abnormal and defective with special needs” before I was even given my name: Camilla N. Gilbert. My parents felt shocked and anxious, but they were never ashamed of me; they encouraged, supported and loved me for who I was. They were also not too focused on the many recommendations from various professionals, audiologists and surgeons, who wanted me to have surgery and ear reconstruction in the late 1980s. My parents declined their suggestions about fixing my ears, preferring to allow me to make my own decision when I was ready.

School of Hard Knocks
My school system seemed to focus on my “disability,” rather than on my capabilities. I recall feeling different at the age of three, when I entered preschool, and according to my Individualized Education Program (IEP), I was different. I was grouped with other students who were different, too. The students in my classes did not look, act or learn the same way the rest of the student body did, nor were we treated the same way. At first, I thought that riding a short, yellow bus to and from school was fun, but I quickly realized that this mode of transportation labeled me as a student with a learning disability, even though I was actually intelligent. For example, I had to leave class ten minutes early just to get on this special bus, and I recall feeling embarrassed because my classmates made fun of me. I often asked myself, "Why do I have to live like this? Why am I so different? Why don’t I have ears like everyone else?"

My physical appearance did not help my self-confidence. I had ears that resembled pizza slices and walked around wearing an uncomfortable, metal hearing aid device. Enduring stares and teasing became norms for me as a child, and I hated it. I used to look down while walking in public to try to avoid the humiliating moments when others would stop, stare, point and laugh at me. I became known as the smart student with no ears, and I was bullied until the seventh grade. I suffered many physical, emotional and verbal attacks simply because I looked different.

My parents may have told me about my condition, but I refused to accept the diagnosis. I just wanted to be normal. To me, being normal was having the ability to plug my ears with my index fingers like other kids, but I did not have ear canals. I longed to play the telephone game with my classmates and hear what they might whisper in my closed ear, but I could not.

As it turned out, though, my experiences of riding the short, yellow bus, learning in a segregated, special education classroom and being bullied by other kids were excellent preparation for the many obstacles I was to face in living with microtia and atresia.

Hiding Behind a Headband
In seventh grade, I discovered cloth headbands, which I used to cover my ugly hearing aid and unusual ears. My cloth headbands became my safety net when I left my house and ventured out into the community. I wore a headband every day, no matter the location—school, friend’s or family’s homes or sporting events—and no matter the occasion—weddings, funerals or parties. I was ashamed to display my uniqueness, so I covered my ears and hearing aid for more than 13 years. In my isolation, I developed low self-esteem, confusion and depression, which continued into my early adulthood.

Embracing Motherhood—and My True Self
I graduated from Central State University in 2005, and I began to be curious about myself. I wondered why I did not have fully developed ears. I began researching
bilateral microtia and atresia. In 2007, I found out I was expecting a baby girl, and I felt ready to take on the role of motherhood. When Jada, my daughter, was born, I had her ears checked and requested a hearing test. Everything was normal! At that time, I was still covering my ears and hearing aid with cloth headbands, but I knew I had to stop hiding from the world. Becoming a mother changed my mindset; I began to accept myself as a woman who happens to have microtia and atresia. By 2009, I had stopped wearing the cloth headbands and began focusing on being my true self and becoming a role model for Jada.

**Connecting With the Hearing Loss Community**

I began seeking ways to connect with people who understood my experiences living with a hearing loss. In 2012, I discovered HLAA and attended my first Walk4Hearing event, where I met others in the hearing loss community who were not only knowledgeable but also proud of their achievements. This was the first time I had experienced a community of others who understood my invisible “disability.” HLAA empowered me to make a contribution to my new community by sharing my story and experiences. I participated in the third annual HLAA Ohio Chapter Leaders Conference in Newark, Ohio, in August 2012; the HLAA Fall 2012 Leadership Training Conference in Bethesda, Maryland, in October 2012; and the HLAA Convention in Portland, Oregon in June 2013. Attending these events enabled me to connect with a caring network and gave me an understanding of leadership roles in the hearing loss community.

Soon I discovered the organization known as Ear Community, which is an online resource designed to help children and adults with microtia and atresia. I was able to meet others with microtia and atresia and attended Ear Community’s Microtia and Atresia Picnic in 2013. I recall feeling excited, overwhelmed and emotional in the company of others who understood the obstacles and challenges that I faced. Parents of children with microtia and atresia and adults with the same condition wanted to hear my perspective, experiences and advice. This experience led me to a new passion: educating others about hearing loss and microtia and atresia, as well as motivating them with emotional support.

Before I knew it, I had become an advocate—before I even knew what advocacy was—for a condition that used to bring me shame. Throughout my life, even with the odds against me, I had always prevailed and overcome any obstacle. As I stepped into an advocate’s role, I felt empowered to offer encouragement to others.
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who have my condition or any form of hearing loss. My creator did not design me to be isolated in my skin but to empower and inspire others to conquer obstacles in their hearing loss journey.

Finally, after a lifetime of wearing analog bone conduction hearing devices, I decided it was time to upgrade and try something new. I chose not to have ear reconstruction surgery. Instead, I consulted medical professionals, hearing loss community members, HLAA and Ear Community associates and decided that the bone-anchored hearing system was the best choice for me, and I had my implant procedure with Oticon Medical in 2014.

Coming Out of My Shell
Society’s correlation of the term “deaf” with the concept of “dumb” had stigmatized me in my youth, so I had long been dismissive of my own culture. I also had a negative association with sign language, since it fell outside of our cultural norm. However, my ideas were beginning to change, and my changing mindset led me to enroll in Cincinnati State Technical and Community College with the goal of becoming an American Sign Language interpreter. In the process, I ended up learning more about myself as a person with a hearing loss. My instructors there were deaf, and they taught me about their language, culture and experiences. I learned that they did not feel abnormal in our society, and that deaf people just want to be themselves. They are not interested in conforming to the standards of the hearing community. This was my “aha” moment, and I began to re-evaluate myself as a person who was born deaf. I realized that I had been misinformed for most of my life about the hearing loss and deaf community. Suddenly, I was on a mission: I wanted to educate and motivate others living with differences to be themselves and resist forced assimilation into a cultural standard that excludes them. This realization forged a new path for me, and I decided to I switch my field of study from social work to education.

Achieving My Full Potential: Advocate and Educator
I am now enrolled in the Doctor of Education in Educational Leadership program at Northern Kentucky University. My purpose is to be an effective educator who offers empathy and motivation to people in the microtia and atresia, hearing loss and deaf communities. I also want to raise awareness of the needs and perspectives of people in these communities. My hope is to challenge those in the hearing community to re-evaluate, restart, regroup and reinvent their preconceptions when interacting with individuals who have hearing loss. I want to reinvent the mindset of people who pity those who were born different. I grew up being stared at and pitied—mostly by people who judged me even when that was not their intention. I hope to educate others through my experiences as a person stigmatized at birth with the “disability” label. I want to inspire those with hearing loss to defeat all odds and become knowledgeable, and I intend to accomplish this through education, advocacy and mentorship.

I have overcome the obstacles of living with microtia and atresia with perseverance, ambition and community support. My challenging experiences provided the foundation for the life I’ve built today because as difficult as they were, they sparked empathy for individuals with disabilities and hearing loss. They also ignited a genuine passion to encourage and inspire others who have endured the stigma of being different from “normal” society.

Becoming an inspiration for those who look like me has motivated me to be a leader and advocate. After connecting with the hearing loss community, I developed the confidence to speak up and educate others. My passionate advocacy for individuals with differences will only continue to grow, and I am proud to be a leader in helping others who feel they do not have a voice.

Camilla N. Gilbert has been an advocate for people with hearing loss for more than 30 years. She is the recipient of the 2015 Oticon Focus on People Award for Advocacy, has served as a board member for the non-profit organization Ear Community, and is a past president of Southwest Ohio Chapter of the Hearing Loss Association of America (HLAA). She is attending Northern Kentucky University for a Doctor of Education Degree in Educational Leadership. She has a Master’s in Social Work from the University of Cincinnati, a Bachelor of Science in Computer Science and Mathematics from Central State University, and a Certificate in Deaf Studies from Cincinnati State Technical and Community College. She can be reached at microtialife@gmail.com. Follow her on Facebook and Instagram @microtialife.