

LettingGO

FALL 2015

ALL ABOUT ME

6 YEAR OLD KENDRA

STUTTERING SUCCESS

AN SLP'S POINT OF VIEW

I STUTTER

GROWING UP ALICE

MIXED EMOTIONS

HEALTH CARE EXPERIENCES

ADULTS WHO STUTTER

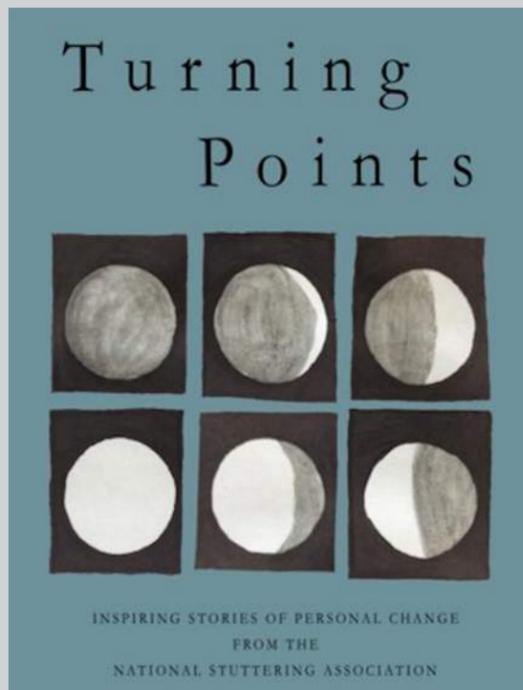
Conference Highlights & Memories

Remembering Sharonda & Ellen

Chapter Spotlight-Nashville

NATIONAL STUTTERING ASSOCIATION

CHANGING THE LIVES OF PEOPLE WHO STUTTER



Almost every person who stutters will experience a turning point—a moment in time when they come to accept their stuttering and embark on living a life without compromise. Before reaching their turning point, each person who stutters must fight past feelings of shame, despair, and loneliness. These dispirited feelings affect more than just the person who stutters: family, friends, teachers, speech-language pathologists, and others are also affected.

TURNING POINTS shares fifteen life-changing stories of courage and perseverance from those affected by stuttering. These stories emerged during the monthly meetings of the Austin, Texas chapter of the NSA.

Those who tell their stories include: students finding their voice in the chaos of college; young and mature professionals finding the fortitude to pave successful careers; a senior on a lifelong journey to find a fluent voice; a parent who shares her emotional path to help her son adjust to stuttering; and speech-language pathologists who empathize with their clients.

Each of the essays in this collection is deeply personal, and yet there are common threads that bind both the stories and the people who tell them. These heartfelt stories will inspire and educate all readers about this misunderstood communication disorder, and help those who stutter find the strength to become their true selves.

Buy it today at the NSA Online Store!

IN MEMORIAM

SHARONDA SINGLETON



Sharonda was one of nine victims killed at the Emanuel African Methodist Episcopal Church massacre in Charleston, SC on June 17, 2015. She was passionate in her career as a SLP for the Berkeley County School District and served as a tireless advocate for many of her students who stuttered. She will be missed.

The National Stuttering Association, the Charleston Chapter of the National Stuttering Association, and Pittard Speech Services, LLC teamed up to create a memorial fund in honor of Sharonda Coleman-Singleton.

Please consider making a tax-deductible donation to the NSA in Sharonda's name. All donations to this fund will help to fund an NSA Family Fun Day in South Carolina.

ELLEN OTTOWAY



Ellen was a long time NSA'er who loved the organization and attended many conferences over the years. We are saddened that she lost her battle with cancer just six days after her diagnoses.

Photo Credit Sharonda: COURTESY STAR MILLER

EVENTS

AUGUST 27:

Rockville NSA Chapter Takes Stuttering Out to the Ballgame

October 2 - 4:

Fall Regional NSA Conference: Tempe, Arizona

October 17:

Greensboro, North Carolina Family Fun Day

October 24:

Boston Family Fun Day, CEU, & Adult Workshop Event

July 5 - 10, 2016:

NSA/ISA Joint Conference

33rd Annual Conference in Atlanta, GA, hosted jointly with the International Stuttering Association.



MIXED EMOTIONS

By Pattie Wood - Family Programs Co-Chair

Another conference is in the books! As usual, this is a time of mixed emotions for me. I spend so much time thinking about the conference, anticipating workshops, contemplating things I want to share, and looking forward to seeing old friends and making new ones, then the days go by so quickly, and before I know it, another conference is over. I spend so much time looking forward to it, yet it is over so quickly. But as usual, I have returned home with my son feeling rejuvenated from all my connections within NSA. What a fabulous conference it was! Family Programs continues to grow and offer every family member of a person who stutters a valuable experience.

This year I had was a mix of emotions for me. After three years on the Board of Directors, my term was ending. I spent many months contemplating whether to stay on for another 3-year term, or to step down when my time was up. Although it was a difficult decision, I decided that since my son, who is the reason I became involved with NSA, is now 17 years old, it was time to step down, and allow him to become more active in his own roles within the NSA. Although I plan to stay involved, (I would never want to lose my connections and support I receive from the parents of NSA), it is time for me to move on from this role that I have enjoyed so much. Thank you to **Tammy Flores, Stephanie Coppen,** and **Sarah Onofri** for being the greatest team to work with.

This was a conference of much reflection for me knowing that my term was coming to an end. My biggest revelation was that after eight conferences, I still need them as much as I did when we began attending in New Jersey in 2007. There are so many ups and downs as a parent of a child or teen who stutters. It never ceases

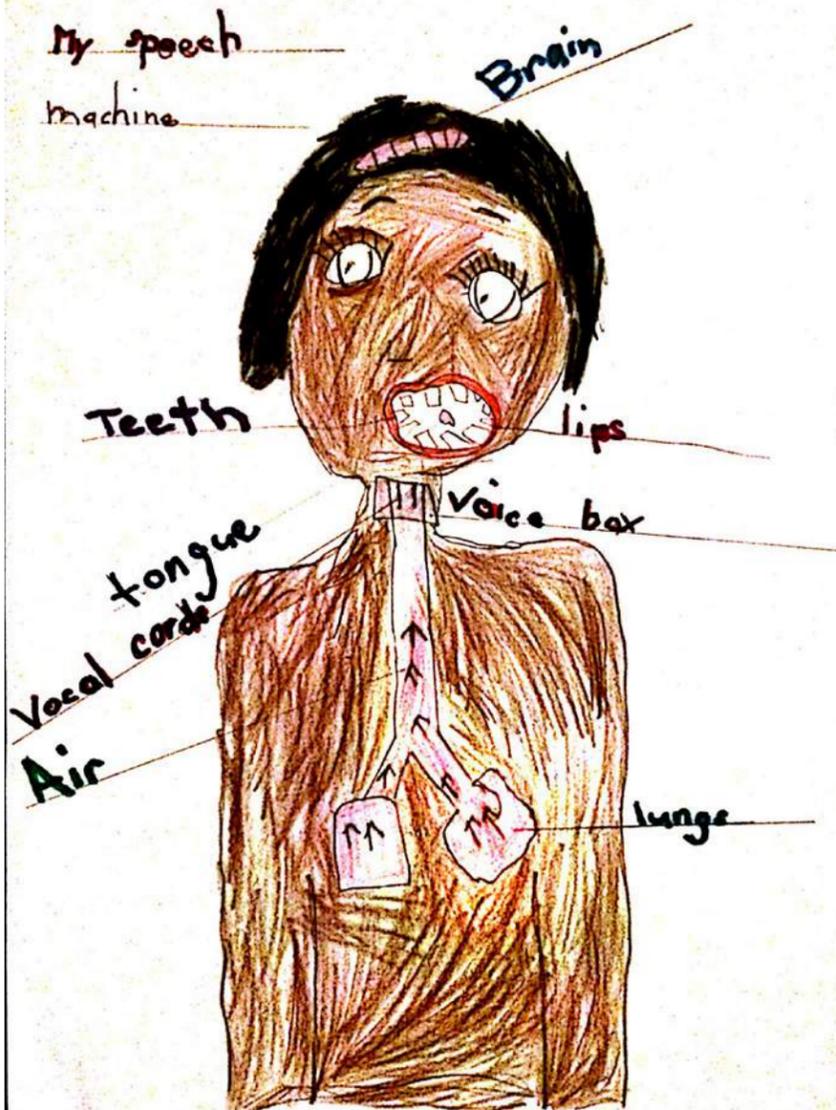
to amaze me how much I need that connection with other parents who understand exactly what I am going through. No matter how old our children get, we are still their biggest support system. But in order to keep performing this task, we need to remember to fill ourselves up as well. So now that we have had time to come home and reflect upon our experiences at conference, remember to stay in touch with your support system all year long. You can do this via the NSA Parents Facebook page. If you are not already a member, do yourself a favor and check it out. What's better than sharing in other parents' concerns and triumphs with their children who stutter?

This conference was one of my favorites yet. The setting in Baltimore was stunning. I know that moving a conference of this size is no small undertaking, and isn't it amazing that not only did the move feel seamless, but the conference was as great as ever? Highlights for me this year were seeing all the wonderful NSA Kids singing *Shake It Off* with Miss Nina both at closing ceremonies and again at banquet, as well as seeing **Michael Kidd Gilchrist** spending time with the kids and teens. There were so many special moments, but one that sticks out to was at the Closing Ceremony when **Max** stood up in front of all 700 people to speak. He may not have been able to say everything he wanted, but every person in that room recognized the courage it took to do this, and that was evident when we all and gave him a standing ovation. This is what NSA is about.

If you have any thoughts or ideas on family workshops you would like to see, be sure to send them along since planning for next year is never far away, and I hope to see you all in Atlanta! ☺

My name is Kendra. I am 6 years old. I stutter a lot and it is ok all the time. Stuttering makes me pretty. I love stuttering. Stuttering is ok. It is a little part of me.

Stuttering
is
cool!



STUTTERING SUCCESS: AN SLP'S POINT OF VIEW

By Amanda Karas

Kendra is a 6-year old female in first grade who presents with moderate to severe stuttering. When Kendra first started coming to speech therapy at the beginning of the year, she would lay her head on the table and cry about the way in which she spoke. She did not want to talk and just wanted the stuttering to go away. Kendra stated that students teased her about the way she talked. Kendra would ask me questions such as "When am I going to stop stuttering?" or make comments such as "No one sounds like me. I just want to stop stuttering!"

Throughout the school year, we have been working on learning about stuttering as well as building her self-esteem and acceptance of stuttering. It is just recently that Kendra has had a breakthrough in speech therapy. Kendra accepts the fact that she stutters. She views stuttering as something that makes her special. Kendra now comes into speech and makes comments such as, "Stuttering makes me feel pretty!" and "Stuttering is cool!"



Kendra considers herself an artist and could not think of a better way to show how she feels about stuttering than to draw some pictures. She wanted to create a book about stuttering so that she could share it with others. One of the greatest moments was when Kendra came into speech and said to me, "Ms. Karas, I want to read this book to my class because they need to learn about stuttering". I told her that she could absolutely show this to her class. When the speech session was over, Kendra and I went into her classroom. She said to her teacher, "Can you please get everyone on the rug, I have something to share with the class". She has even met with a student in fourth grade who also stutters to help him understand that stuttering is okay.

"MS. KARAS, I WANT TO READ THIS BOOK TO MY CLASS BECAUSE THEY NEED TO LEARN ABOUT STUTTERING".

Kendra has made tremendous progress in speech therapy. Words cannot even express how proud I am of Kendra. As I reflect upon

who Kendra was and who she is now, it brings tears to my eyes. I reflect upon the progress she has made and I find it hard to believe that this growth, progress and insight has been accomplished in such a short amount of time by a 6-year old. Kendra will forever be that student that I remember year after year and the one that continues to inspire me. When I think about someone who deserves to be recognized for her progress in speech therapy, Kendra is the first person I think of. As a result of speech and language therapy, her life and educational experiences have been positively impacted.

Kendra has come such a long way and is now comfortable with the fact that she stutters. Speech and language therapy has helped Kendra to make tremendous gains in her life and educational experiences. Kendra's participation in class has improved and she is now able to stand up for herself. Kendra thinks that stuttering is cool. She has enjoyed sharing this book with her friends, family, teachers and classmates. Kendra is a role model and an individual that does not let stuttering define who she is. Kendra is proud to stutter and wants everyone to know that it is okay to stutter!



2015 CONFERENCE RECAP

By Tammy Flores

Each year, the National Stuttering Association (NSA) hosts the largest national gathering for children and adults who stutter, their families, and speech professionals. With over 700 attendees, this four-day conference attracts attention across North America, creating a safe space where participants can learn about the latest stuttering information and find support for themselves and their loved ones.

In the days before the start of the Annual Conference, the NSA Research Symposium brings a cross-section of experts including early intervention strategies, the latest research, evidence-based treatment approaches, and more. What makes us stand out amongst the other professional conferences is the number of researchers and presenters who stay for the entire conference after the symposium ends. Some present their findings in workshops while many others stay to support their clients while learning first-hand what it is like to be a person who stutters. Where else can a student who is just starting out in their speech pathology career share a meal with one of the top in the country? I find this so cool!

This year's conference theme brought us to Baltimore - "Charm City" - where the city's nickname certainly lived up to our expectations and made us all feel right at home. Charmed we were! With easy access to the Inner Harbor and waterfront, time was made to be certain we could all take advantage of the local attractions. I am happy to report that, despite last minute changes, again our numbers rose as we topped out at 710 people attending, with 198 of them as First Timers!

Workshops began on Wednesday with a fun icebreaker. An expanded First Timer's program included an informative workshop and luncheon to welcome new adults and families upon their arrival. Open to all, our summer Board of Directors meeting had many members sit in to learn about the goals and plans of the NSA.

Like every year, an array of workshops provided all attendees with great takeaways, including special workshops for the youth with art projects and scavenger hunts designed to explore stuttering and engage awareness. Teens discussed 'hot topics', 20-Somethings shared strategies, and parents and adults shared a wealth of information. From Toastmasters to movement, workshops left all of us feeling motivated and supported.

We work hard each year to live up to our reputation of having inspirational keynote speakers and special guests, and this year was no different. An inspiring panel of professionals including **Edward Neufville**, **Carlos Vegh**, **Jenny Maguire**, **Frank Flannery**, and **Chris Anderson** gave first hand examples of how stuttering does not get in the way of achieving dreams, while **Leana Wen** moved us with her personal stories filled with humor and perseverance. And, how can we forget NBA star **Michael Kidd-Gilchrist**, who stuck around and enjoyed an afternoon of workshops.

Each year there are always several experiences that stand out, moving me so much that I know I will never forget them, and this year was no different. Long time NSA'er **Landon Murray** shared his conference with his mom who was attending for the first time. Hearing his mom speak openly at the closing ceremony about her feelings as a First Timer and share her emotions as a parent who has worried about her son for so long was touching. To hear her praise and acknowledge his strengths moved the entire room. This is why I continue to admire the support shown at these conferences and all year long.

Every year the team of individuals working behind the scenes grows. 'Thank you' is never enough to all of you who worked extra hard this year to move our conference and make it one of the best yet. With sincere appreciation, I want to thank **Melissa Lopez**, **Brandie Flores**, **Joan**, **Dave & Heather Ross**, **Annie Bradberry**, **Jim & Lee Lowman**, **Tony Romano**, **Mandy & Jean Finstad**, **Steph Coppen**, **Sarah Onofri**, **Nina Zito**, **Pam Mertz**, and **Vivian Sisskin**. And our dedicated **NSA Board of Directors**, I want to thank each of you for your support and tireless efforts.

We are still unpacking and yet talk of next year has already begun. Each year I take home with me the love and support that is felt when we come together, and like you, I can't wait to get together again. Each and everyone one of you are the reason why the conferences are a great success, and I thank you for your commitment to making sure we continue to be the largest national gathering for children and adults who stutter. We have many more people to reach, but together we can make it happen. See you soon in Atlanta 2016! ☺



THE HEALTH CARE EXPERIENCES OF ADULTS WHO STUTTER: AN ONGOING INVESTIGATION



By Perez HR, Doig-Acuña C, Starrels JL. “Not Unless It’s a Life or Death Thing”: A Qualitative Study of the Health Care Experiences of Adults Who Stutter. *Journal of General Internal Medicine*. 2015 Apr; [Epub ahead of print]

As a physician who stutters, I’ve always been fascinated by communication in the medical office between doctor and patient. I’ve been on both sides of the clinical encounter, and I became interested in finding out more about how persons who stutter interacted with their doctors and the medical system. I found the research in this area to be limited, so I sought to seek further answers through a clinical research project.

While in medical residency, I sought the help of the National Stuttering Association in order to conduct a qualitative study of persons who stutter about their health care experiences. A qualitative study is a special type of research study in which researchers ask participants open-ended questions and seek to create a better, more thorough understanding of a phenomenon. Researchers have qualitative methods to examine a litany of stuttering related experiences, including the general experiences of adults who stutter (Corcoran and Stewart 1998), the effects of stuttering on employment, education, and self-esteem (Crichton-Smith 2002), and the effects of self-help conferences on people who stutter (Trichon and Tetnowski 2011). Our goal from the start was to write primarily for a medical audience to introduce many to the unique experiences faced by persons who stutter in the health care system.

We recruited sixteen adults to participate in three focus groups at the 2012 National Stuttering Association conference in St. Petersburg, Florida to discuss how stuttering may or may not affect their medical experiences. Participants ranged from 18 to 75+ and most (75%) described their health as Excellent or Very Good. The majority (88%) had at least one doctor they considered a Primary Care Doctor. Most (75%) also rated their stuttering of “Minimal” or “No” concern.

After analyzing audiotapes and transcripts with a group of

researchers at Montefiore Medical Center, we described five ways in which stuttering affects interactions with the medical system. Participants described (1) discomfort speaking with office staff and physicians, which resulted in (2) avoiding health care interactions because of stuttering, and (3) relying on a third party to navigate the medical system. Moreover, during visits with physicians, participants felt that (4) discussing stuttering with physicians required trust and rapport, and (5) speaking assertively with physicians required self-acceptance of their stuttering.

Ultimately, we concluded that even in this healthy group of participants with minimal concerns about stuttering, there were communication barriers inside and outside of the medical office that could have an impact on health and health care. Even when stuttering had negative health consequences including anxiety or depression, participants reported some reluctance to discussing it with their physicians. Self-acceptance, on the other hand, had a positive effect for participants in communicating with their doctors. This may lead to more assertive behaviors, with one participant saying about time pressure in the doctor’s office: “I have to say what I need to say in the time I need to say it. You’re going to have to wait.”

This qualitative study is a first step towards understanding how stuttering affects medical interactions. Additionally, we recently completed a broader survey-based study among persons who stutter to further assess medical experiences; results are forthcoming.

References:

Corcoran, J. A., & Stewart, M. (1998). *Stories of stuttering*. *Journal of Fluency Disorders*, 23(4), 247–264.

Crichton-Smith, I. (2002). *Communicating in the real world: accounts from people who stammer*. *Journal of Fluency Disorders*, 27(4), 333–352.

Trichon, M., & Tetnowski, J. (2011). *Self-help conferences for people who stutter: A qualitative investigation*. *Journal of Fluency Disorders*, 36(4), 290–295. ●

CHAPTER SPOTLIGHT



NASHVILLE, TN

Each year, members of the Nashville Adult NSA Chapter speak to students who are preparing to become Speech-Language Pathologists at local colleges and universities about stuttering and the challenges faced by people who stutter, including undergraduate students at Middle Tennessee State University and graduate students at Vanderbilt University. The chapter members have also spoken to graduate students at Tennessee State University after the NSA Annual Conference, where they were able to share the information obtained from the conference.

This year one of our newest NSA’ers, **Mena**, originally from Egypt, became a naturalized US citizen along with his wife, and a few of the chapter members were able to attend the naturalization ceremony in support. Mena thanks the NSA for helping to improve his self-image, since in Egypt, he was ostracized by his family and society.

The Nashville Chapter has also enjoyed quite a bit of positive press, such as Nashville Public Radio’s coverage of their journey to form a Toastmaster’s club for people who stutter and an article in the Toastmasters International newsletter.

The Bill Wilkerson Toastmasters is the third and newest club for people who stutter, and for their supporters. Demonstration meetings started in May 2014, and the club, based in Nashville, Tennessee, chartered toward the end of the year. The club mentor is **Eugene Johnson**, and it was his experience that drove the formation of the group. For many years, Johnson’s stutter caused him to avoid conversations with people, even though he describes himself as a natural extrovert. He joined a Toastmasters club in Nashville—The Parthenon Club—three years ago, and now he not only is confident in conversations but speaking in front of groups. “I no longer have the fear of stuttering, which is a major hurdle to overcome for a person who stutters,” he says. Because of his success in Toastmasters, the staff at Nashville’s Vanderbilt University Stuttering Foundation Program is sponsoring the Wilkerson club. These Toastmasters, and other members around the world who stammer, prove that it’s possible to face your fears and succeed.

The chapter also hosted a special screening of *The King’s Speech* at the Franklin Theatre, one of the historic movie theaters in the Nashville area to celebrate National Stuttering Awareness Week. The group was successful in reaching out to the Nashville/Middle Tennessee community and bringing awareness to stuttering via multiple news articles, television programs, and radio stations, as well as various social media outlets.

Well done, Nashville Adult NSA Chapter! Keep up the great work!

I STUTTER



By Alice Murch Smith

Getting ready for the first day of school always caused me to get ‘butterflies’ in my stomach; I knew within an hour I would be walking into a sea of uncertainty. I gathered with the other children who lived in my neighborhood down the street and waited for my bus to arrive. As the flashing yellow lights approached, I remember thinking to myself, “Here it is. This is it, Alice, this is the point of no return. You can’t go home after this.” I took a deep breath and boarded the bus. Children piled into the school, socializing obnoxiously with one another, each of them sporting smiles on their faces. I envied every single one of them; their happiness was effortless, and so was their ability to make friends.

My classmates eagerly made their way to their new classrooms. I sluggishly walked in and took a seat. My new teacher was a short, half-bald, older man with a slight hunch. He got up from his desk and stood quietly in the front of the room until he eventually gathered everyone’s attention. I started to tremble as anxiety quickly took over my body. I knew that this was the moment I’d been dreading since my alarm clock went off earlier that morning.

“Okay class, let’s go around the room and introduce ourselves.” Following the professor’s directive, each of my peers stated their name and a fun fact about themselves. As it was getting closer to be my turn to speak, I noticed my palms were starting to sweat and my throat was getting dry. Only two more students needed to state their names. I suddenly caught a wave of lightheadedness; I could feel the adrenaline pumping. One more student left. I could barely breathe; my heart was pounding so hard I could hear it echoing in my head. It was my turn. I stood up and cupped my hands together to try to stop the nervous shaking. “Here it goes” I thought to myself. I opened my mouth to say my name and nothing happened, not a single sound was expelled. I glanced up shamefully and skimmed over what seemed like to be miles of blank stares and cruel

I NEVER REALLY NOTICED I WAS DIFFERENT FROM EVERYONE ELSE UNTIL A LITTLE GIRL IN SECOND GRADE POINTED OUT THE FACT THAT I TALK FUNNY.

smirking grins. I took a deep breath and tried again. “H-h-h-i. M-m-my na-n-na-name is A-a-alice.” Instantly after finishing that grueling sentence I heard muffled giggling coming from several places in the room. “She’s retarded,” a boy whispered to his friend. My eyes started to look like glass as the humiliation grew. I sat down immediately and sunk into my seat wishing that day had never happened.

I have stuttered since I was 5 years old. For the most part, however, I felt like a normal, carefree, child. I never really noticed I was different from everyone else until a little girl in second grade pointed out the fact that I talk funny. “I talk funny?” I thought to my 7-year old self. That was the first time I realized there was something ‘abnormal’ about me. I became aware that I was different, but mostly, I lived my life to the fullest. My stutter had not yet started to cripple me.

After several years of speech therapy my stutter was seemingly under control, but that wasn’t necessarily true for my confidence. Once I started middle school, bullies taunted me daily. In my opinion, children in middle school are the worst when it comes to bullying because of their age group. They are in-between childhood and adulthood, nearing the crest of adolescence, and for some reason they just don’t seem to have much of a grasp on the differences between right and wrong. For me, going to school was torture and I dreaded every single day. I worried about everything. I would think about what would happen to me that day, would I be asked to read out loud? What if the teacher makes me read? What if people laugh at me? What if I can’t say my own name? Walking down the halls at school, people would stare at me and whisper things to their friends. Worst of all, they would mimic me. “Hi st-st-st-utter g-g-girl,” they would say. I would roll my eyes and ignore them, but their knives sunk deeper. My mother even came to school to speak with the principal about a girl who was leaving cruel notes in my locker.

Towards the end of middle school my quality of life improved. I had finally made some friends who were in the stereotypical ‘nerd’ group, in which I happen to fit perfectly. We all had flaws, but because bullies taunted each of us, we all stood up for one other. My best friend was a morbidly obese 13-year old. She had carrot colored hair and was the biggest girl in school. She endured just as much bullying as I did during our grueling three years at that

school; eventually the bullying got so bad her parents transferred her to a different school.

Believe it or not, kids aren’t the only ones who are bullies. I have one distinct memory that constantly replays in my mind, and to this day, nearly ten years later, it still causes me significant amounts of pain. One day, in the seventh grade, my history teacher called out for a family emergency. The school hired a substitute to take over the class and teach that day’s lesson. He decided to go around the room and have everyone read a couple pages of the textbook. This may be the worst teaching method ever. I instantly had a miniature panic attack. “What do I do? Ok, calm down. I’ll just ask him if I can be skipped and it will be ok. He will let me pass.” In the past, whenever in this situation, I would fake being ill and ask to go to the nurse so I could skip the humiliation of not being able to read without blocks. This time, however, I had faith in the substitute teacher, thinking he would be compassionate about my speech impediment. I was sorely mistaken. His reaction was quite the opposite; he forced me to read out loud, even after I told him the reason why I couldn’t.

I suffered through the first paragraph, stumbling on almost every word. I was so embarrassed; my face was bright red. My voice was cracking because I was trying, with all my might, to hold back the tears. Some of my friends could tell I was suffering and kindly volunteered to read for me. I know they felt bad for me because the substitute was making everyone suffer through the reading; we all knew what he was doing was cruel.

I am now a twenty-two year old woman and no longer let my stutter control my life. I do things now that I never thought possible before. In college, I engage with my classmates and participate in group conversations. I have become much more outgoing, mostly because the majority of people I meet are very understanding of my speech problems. Even though I will never forget the bullies of my past, nor their unkind words, I feel as though I have become a better, stronger person by having gone through those experiences. Occasionally I’ll catch myself worrying about silly things such as messing up my wedding vows, or not being able to give my best friend the proper wedding toast. But then, I just breathe, and remember that without stuttering, I wouldn’t be the kindhearted person I am today. ∞



JULY 05  JULY 10

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... *Georgia* ...

33RD ANNUAL NSA CONFERENCE
{ 11TH ISA WORLD CONGRESS FOR PEOPLE WHO STUTTER }

2016

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JULY 5-10, 2016

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