

# Family VOICES

FIRST QUARTER 2014

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## Giving Back

JENNY ADAMS, FL

We all have something very special in common. Besides being parents to amazing children who stutter, we are a part of something bigger. We are blessed to be a part of the National Stuttering Association. We all have our own unique story about how the NSA has changed our lives, but no matter the details, we all couldn't make it through this journey quite so seamlessly without the support of our NSA family.



Without the generosity of many financial contributors, our attendance at previous conferences would not have been possible. Without those financial contributions, my daughter Jada and I would have never been able to experience the NSA conference that turned our world around. Jada would never have met friends who stutter just like her, around whom she can feel comfortable just to be herself and not be judged. I would never have met the amazing women who support me on a daily basis and who really "get" the struggles that I have with Jada, even when it isn't about stuttering. Without those financial contributions, the NSA would not be able to provide a conference experience like no other for hundreds of adults and children who stutter and their families that all "get" our struggles and share our triumphs.

In honor of International Stuttering Awareness Week I wanted to give back to this organization that does so much for so many. I am an Independent Designer with Origami Owl, a custom jewelry company, and for the entire month of October I held a fundraiser for the NSA where all of my proceeds went to the NSA. With the help of many of you, we were able to raise \$260 for the NSA in just two weeks!

I challenge you, and your families, to think of ways that you can give back to the NSA. Think about what the NSA means to your family and where you would be without it. ::

*...for kids, 'tweens,  
and teens who stutter,  
their families,  
SLPs, and others  
who support them!*

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and Twitter today!

# Ask the EXPERT

REUBEN SCHUFF, NORTH CAROLINA



**In this issue of Family Voices we are mixing things up a bit! This issue's 'Ask the Expert' piece is written by Reuben Schuff, long-time NSA member and adult who stutters. Reuben generously shares his journey with stuttering through different times in his life in a unique and inspiring manner.**

## **In this Moment in Time**

In this moment in time, I reflect on the journey of the past, present, and a future yet to be written. So far it's been the ride of a lifetime, and I still have a ways to go. My journey with stuttering goes far beyond the sounds and syllables of spoken language, and fills my life with what it means to communicate. If me, myself, and I could write to each other, it might read something like this.

### **Nov 27, 1997**

Dear Future Me,

I turned 16 this month and bought my first pickup truck. It's a bucket of rust, but it's my pride and joy, hard-earned from washing dishes, bussing tables, and cutting grass in the summer. I wonder where you are 16 years from now. You know, the guy who sold me my truck treated me like I was pretty dumb. I guess I can't really blame him. I struggle pretty massively with my speech, and jerk around a lot to force out the few words I can manage. I must look pretty ridiculous, and I just try to talk as little as possible. I'm working on some techniques with my school's SLP to help me learn to be fluent. She recently introduced me to a delayed auditory feedback device. It was really expensive and we had to talk to the Special Ed department to get them to buy one for the school. My SLP is really nice and tries to help me, but I know she doesn't know much about stuttering. I know I need to find a way to beat this demon and speak fluently, but I'm not sure how. No one really gets what it's like to struggle to get every sound out of your mouth.

I'm wondering, how will things turn out for me? It's always been my dream to become an aerospace engineer. I do well in school, but I really worry about the stuttering. Each year, I think I'm going to figure out how to beat it and learn to be fluent, but each year that doesn't happen. I get my 30 minutes a week with the SLP at school, and we practice some sound exercises to try to stop my stuttering. I do pretty well in the little therapy room, but nothing works in the real world when it matters. I just end up thrashing. I was supposed to grow out of this. I just want this to stop. Why does saying everything have to be so hard?

### **Nov 27, 2013**

Dear 16-Year Old Me,

First of all, I want to tell you congratulations. I know you were worried how all this was going to work out. I want to let you know, in fairness, that's it's been a rough, rocky, jagged road. And so far you've risen to

the challenge! I know you've always been resolved to not let the demon of stuttering beat you, and well, you've fought the good fight. 'Beating stuttering' didn't happen in the glorious parting of the waters that you'd hoped. I'm pleased to let you know that you made it through high school, barely, but that still counts. You did well in college and got that aerospace engineer degree you were chasing, and then a Master's degree. You struggled through a lot of hard days as you started to understand that stuttering isn't just about words that get stuck. It's about communication that needs to happen, and even more, learning to *enjoy* communication. They forgot to tell you that speaking is supposed to be fun and not some burden to bear.

You made a way at your first job post-college working on NASA and aerospace military contracts and figured out that you had to have a voice, **even when you stutter**. You've done well to forge a career, and have always followed your heart and your dreams. You've not learned to relax very well, or take it easy; slowing down just isn't your style. Life is fast and difficult, and so are you, and I think that's ok.

If there were one thing I wish I'd known, it would be this: the ultimate goal is to COMMUNICATE – effectively, efficiently, and enjoyably. Stuttering less, and more comfortably comes from focusing on the communication; and trying not to stutter as a means to improve communication only leads to struggling more fiercely. This is the ultimate paradox of life, the universe, and everything. People will praise you for not stuttering; smile, and understand they mean well. People will reprimand you for showing stuttering; smile and understand they mean well. People will offer ridiculous suggestions for how to stop stuttering; smile and understand that they mean well. People will be mean and try to cut you down; smile and know that they are very small in a world that is very big. A precious few people will have a wise and unique understanding of the nature of the disorder. They will help you; smile, and treasure them. Surround yourself with people who are doing hard things and making positive changes in their lives. All things are possible.

Thanks for hanging in there on the hard days. I know it's been tricky, and it's been worth it.

### **Nov 27, 2013**

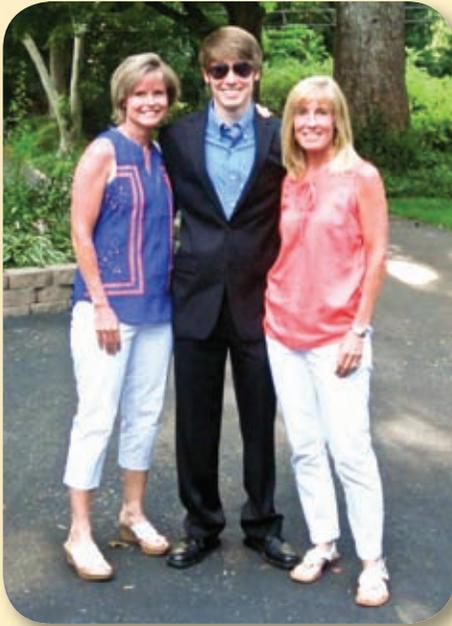
Dear Future Me,

By magic I hope you read this 16 years from now in 2029. You'll be 48 (wow) and probably have lost

*continued on next page*

# A Message FROM:

BEN NORTH, OUR NEW TAC CHAIR!



**My name is Ben North.** I am a freshman at the Catholic University of America, and after six NSA conferences and three years on the Teen Advisory Council (TAC) it is my pleasure to take over the position of TAC Chairperson. Throughout my years at the NSA, I've learned so much about what it means to truly own my stuttering and I've become part of a second family, much bigger than myself.

When I first started attending the conferences, I had a hard time meeting people and making friends. This was because I felt bullied by a kid my age that obviously did not understand what the NSA was about. However, it only took one year for that to completely change; the following year I met my best friends and it was then that I felt the power that is the NSA. Even though I had only met my new friends that day, it felt as though I had known them my entire life, because they understood me in a way that no one else could. After experiencing this I wanted to give back, so I applied to the TAC, and I was brought on in 2011 at the Fort Worth conference.

As a TAC member, I wanted to make sure no one – especially first timers – had the initial conference experience like I did during my first conference. I try to be as inclusive as possible and meet as many first timers as I can at each conference. I feel that this is the most important part of being on the TAC, making sure that every kid and teen has the full “NSA experience”. In working towards that goal, the TAC completes many outreach projects throughout the year, in addition to hosting the *NSA TwST Live!* Google+ hangouts. In order to be role models to the kids and teens of the NSA, we are always working to raise awareness and make fellow stutterers feel welcome. I'm honored to lead this awesome group of people, and to help the NSA grow. ::

## Ask the Expert *continued from previous page*

your hair. Maybe you'll have a family and kids – who knows, all things are possible. My wish for you is that you've used every day you've had to be the best you could. I hope that you have communicated powerfully and taken each day as an opportunity to grow, learn, and give. At the time in my life that I am writing this, I co-lead a self-help group for kids and families of people who stutter. I am a Toastmaster public speaker and I relentlessly put myself on stage to become a better presenter and speaker. I am an engineer and I work hard to serve my team and my company as best I can. My role has changed from age 16 to age 32 and I am sure it will change even more by age 48. My wish is that my challenges have strengthened me, and helped me to lift up those around me. It is my hope, my plan, and my daily goal to communicate better than I do today. And along the way, I will surely learn and grow, achieve and fall, rise and hurt, heal and discover connections, and speak from inside of my heart. Life is a journey, so keep on moving! ::

## Upcoming Events

### February 7-8, 2014 | Washington, DC

NSA Board of Directors Winter Meeting

### March 22, 2014 | Royal Oak, MI

Michigan Family Fun Day | CEU  
Beaumont Hospital

### March 22, 2014 | Tampa, FL

Tampa Sixth Annual Speech Party | CEU  
University of South Florida

### April 5, 2014 | Omaha, NE

Omaha Family Fun Day | CEU  
University of Nebraska

### July 2-6, 2014 | Washington, DC

NSA 31st Annual Conference  
Renaissance Washington, DC Downtown Hotel

# Pursuing Your Passion!

CORA CAMPBELL, CA

My name is Cora Campbell, and I have been an active member of the NSA for almost three years. I lead the Temecula, California NSA Chapter and I am finding out just how much I love –and am challenged by - this wonderful opportunity. Recently, I was promoting our chapter through a local radio station and the topic of the show was, “How to Pursue Your Passion.” It can be so difficult to find out as young adults want to do with our lives, but it occurred to me that finding what you love to do isn’t as difficult as it seems.

For a few years during and after high school, I went back and forth on choosing the “right” career path. I had interest ranging from fashion to massage therapy to speech-language pathology. In high school I took a sewing class and I enjoyed it, but wasn’t sure if I really wanted to spend my days in the fashion world. After high school I found a message therapy school and went on an interview to see if that industry would be a good fit. During my interview my speech was such a mess. I couldn’t even speak to the coordinator who led the program. I felt so embarrassed and misunderstood during that interview. Finally, I decided to look into speech pathology. After a few weeks of research, I found a Speech-Language Pathology Assistant Program that I thought I would really enjoy. As a person who stutters, I might be able to give SLP’s a unique understanding of stuttering, and I believed I would be able to relate to people who stutter in an understanding and compassionate manner.

As it turns out, the SLPA program was a perfect fit for me! I met the wonderful speech-language pathologist who lead the program and taught many of the classes, and I was pleasantly surprised to learn that there were other people with communication disorders who were also applying for the same program. It felt like home – a place where I could feel comfortable and grow both as a person who stutters and as a professional. I loved learning about speech and language and I found something that I was naturally good at - helping others.

Finding my passion wasn’t that difficult after all. I just needed to listen to my instincts, find what I was naturally good at, learn more about it, talk with others who were in the field, and find a program that was a good fit for my passion. Whether, you’re interested in music, art, psychology, biology, or video games, whatever it may be, remember, there is always room for you to grow within that area and seek out others who are like-minded and driven. Imagine doing something you love everyday for the rest of your life. Your career can be something you love and enjoy doing. It’s an amazing experience be able to go to ‘work’ every day and love what you’re doing with peers who are passionate about the same things you are!

Needless to say, the NSA has pushed me to a whole new level of confidence, enthusiasm, and excitement. I am so grateful to be able to continue my efforts and expand my passions of supporting, empowering, and helping others who stutter! ::



## The Great Support

At the recent Family Fun Day in Phoenix, AZ, McCall C. (age 10) wrote this touching poem for her brother Carter C. (age 14), who stutters:

*Though anguish, frustration, and defeat envelope him,  
The rhythm of his words begin.  
The pulse of hope,  
The height of joy,  
The lifting of his chin.  
The pride stamped upon his face,  
The great support we offer him.*





### Unleashing the Silence

DANITA B., TORONTO

*They look perplexed, as someone's choking me  
The look in their eyes shows little patience  
Embarrassment grows; I want to break free  
Is this happening? This situation?*

*I spit it out quickly and gasp for air  
I finish, my heart is palpitating  
Their expressions - ridiculous I swear  
I thought I was just hallucinating*

*They look like giants; they have shrunk me  
My words are stuck, like traffic at rush hour  
"Spare me your pity!" screamed my thoughts in plead  
The King had it too, though he empowered*

*This will not tame me, endeavour I will  
Not an abnormality, just a skill*

As you know, the National Stuttering Association is dedicated to bringing hope and empowerment to children and adults who stutter, their families, and professionals through support, education, advocacy, and research. A few of the most effective ways that we are able to honor our mission and reach out to families in need of support is through our Family Chapters, Family Fun Days, and CEU's for professionals. NSA Family Chapters (TwST & Kids) provide kids and teens who stutter and their families the opportunity to meet regularly. Whether that means having a structured meeting or getting together quarterly for pizza and bowling, families find these activities extremely beneficial.

Deciding to start a Family Chapter and becoming a Family Chapter Leader can seem daunting, but Family Programs would like to assure you that we are here to support and assist you in creating a chapter that meets the needs of each individual group. Building and maintaining a successful and sustained Family Chapter is extremely rewarding and while there are certain procedures that must be adhered to, such as the safety of chapter attendees, we encourage each Family Chapter to create their own 'personality' to best meet the needs their members.

NSA Family Fun Days and CEU's have really taken off over the last few years! These unique events, held all over the country, are best described as 'mini-conferences'. The NSA is pleased also to be able to offer CEU's – continuing education programs – for speech-language pathologists. The NSA offers CEU's presented by a speech-language professional whose focus, education, and interest is specifically in stuttering. CEU's present a fabulous opportunity for SLP's in schools and private practice to take what they've learned about stuttering and apply it in a therapeutic setting with their students.

Family Fun Days are half-day events that offer workshops for kids and teens who stutter and their families in addition to providing a continuing education opportunity for speech-language professionals. It is especially gratifying to organize and hold these events, since many kids and teens would not otherwise have the opportunity to be with other people who stutter, and parents and professionals who provide support to the stuttering community are able to connect with one another. At a recent Family Fun Day I was touched and inspired by the excitement of a young lady named Jillian who couldn't wait to meet other kids who stuttered and by a young man named Paul who said to me, "When my mom told me we coming I didn't want to, but now that I'm here I don't want to leave!" Knowing that the NSA and the work we do has such a profound effect on these wonderful kids reaffirms my commitment to helping, supporting, and empowering them and their families.

If you want to make a difference in the lives of young people who stutter and those who love them, please consider starting a Family Chapter or hosting a Family Fun Day/CEU in your area. We need your help to continue our outreach to those who stutter and may feel alone. Please contact me at [SCoppen@WeStutter.org](mailto:SCoppen@WeStutter.org) and I will be happy to work with you to develop a chapter or an event that best suits you and your potential attendees. Remember: If you stutter, you are not alone! ::

**National Stuttering Association**

**t.w.s.t.**  
Teens Who STutter

**nsakids**  
national stuttering association

# Advertising on ISAD

BEN NORTH AND THE TAC

**For International Stuttering Awareness Day, each member of the Teen Advisory Council (TAC) advertised to members of their community about stuttering, the NSA, and ISAD. The goal of this project was to show the “ins and outs” of advertising in different situations, as well as the results of advertising. The TAC shared some very interesting stories about their experiences:**

“I made it a goal to advertise my stuttering to someone AT LEAST once a week. Whether it be a professor, one of my classmates, my roommates, or my friends. I started at a new University this year, so I had many people to advertise to, and I would say I ended up advertising my stuttering to someone every single day! I told them all about the NSA as well. On ISAD, I wore my “Keep Calm and Stutter On” t-shirt, and I asked my Psychology professor if I could do a short presentation to my class about stuttering.” – *Alex D.*

“This year, International Stuttering Awareness Day was very different for me than in past years. Last year, I was in eighth grade in a very small school. I didn’t really advertise my stuttering much because everyone there knew me. This year, however, I am a freshman in a very large high school. Being in a new environment was hard for me at first. I was so afraid to talk to people because they might hear me stutter. I am usually a pretty open person but when it comes to my stuttering I am very shy. However, on ISAD this year, I really wanted to come out of my shell a little bit. I decided to advertise my stuttering to the people sitting at my lunch table, and everyone was really nice about it!” – *Danny W.*

“This fall I started my first year at Catholic University, and I made it a goal to advertise to everyone that I started to hang out with. This led to a variety of reactions, which ranged from people that thought it was inspiring, to people who didn’t care, and even to people that started to make fun of me because of it. However, the vast majority either thought it was inspiring or said that it didn’t impact their perception of me at all. This just goes to show that, even though there will always be those people that make fun of us. Most people respect us because of the struggles that we go through every day, and advertising gives us a chance to see that for ourselves” – *Ben N.*

“For my International Stuttering Awareness Day project I gave an informative speech on my school’s morning announcements. A fellow stutterer and I pre-recorded a small speech that explained what stuttering was and included some “do’s and don’t’s” about how to interact with a person who stutters. It went very well and I got a lot of positive feedback from friends, along with people who asked me

questions about stuttering as well as people who recognized my face in the hallways and started up conversations about stuttering with their friends. I feel that this is a very good way to get the word out in school and I look forward to doing it again in the future.” – *Dan H.*

“She didn’t really understand, so we just kind of forgot about it. Just thinking about it makes me cringe. I had never known what it felt like to advertise and put yourself out there to just fall flat. People only tell you about the good stories, not the bad days or the rude people or just being misunderstood by someone you wanted to be close with. It is a hard pill to swallow but you move on. Life goes on because as stutterers, I believe, we were made for this. All the craziness will someday make sense. Though it may take longer to say things, what you have is worth saying. Never forget it.” – *Katie D., after advertising to a girl in her class who had laughed at her stutter in her school presentation*

“For my ISAD assignment I did several things. Among them I wore my “Keep Calm and Stutter On” shirt to school and the response was huge. So many people told me how awesome they thought it was and they asked questions pertaining to my speech as well. One person asked at what age I started stuttering. Even a simple question like that left a positive effect on the stuttering community because now one more person knows more about stuttering.” – *Eddie B.*

“One of the persons I advertised to about my stutter was not, in fact, planned. I met this person while waiting for the dining hall to open on my campus. She asked me a question, one thing led to another, and we just struck up a conversation. To my surprise I was talking to her for the rest of my time at the dining hall. One of the conversations we had involved me advertising to her that I have a speech impediment. Out of my surprise, when I said that I stutter, she didn’t question me about it or express any sympathy. She just continued to listen to me talking like I didn’t have any disability. My time at Rutgers, in fact, has been filled with these instances where people continue to listen to me speak, in spite of my stutter!” – *Bryan C.*

Advertising can be one of the hardest things for us stutterers, and even though there can be those people that make fun of us and try to shatter our self-esteem, we get right back up and find people that like us for who we are. More often than not, advertising is a positive experience, and even though it can be terrifying at times, it becomes really rewarding. ::

# My Journey

RYAN B., MICHIGAN

My name is Ryan and I'm nine years old. As far back as I can remember, I have stuttered. I wake up every morning and I wonder what my speech will be like that day. I wonder if I'll get picked for kickball or if I'll get passed over again because I stutter. I wonder if I'll get so mad because someone is laughing at me when I talk that I start yelling at everyone again including my friends. All of this happens before my feet even hit the floor.

I started stuttering when I was four years old. My mom took me to see a speech therapist not long after that, and once I started kindergarten, I started seeing an SLP twice a week. Her name was Mrs. Sherbel and I really liked her. At first I thought she was going to fix how I talked, so I went gladly every time she pulled me from class. We played games and I learned different ways to say my words like stretching them out or taking a breath or pausing between them. It was so hard to do what she was asking me to do but I tried. It made me so tired but I did it. It was all so easy inside her office, but every time I left her room and tried to use the tools that she taught me, I failed. Then, my stutter seemed to go away and I thought that I had won. I was wrong. My stutter came back and it was worse than it was before. I couldn't even say my name or talk to my friends. All I could think of was what's it going to be like when I can finally talk normally. When was I going to be normal? I hated what was happening to me. I worked hard at school but when I got home, I didn't have to try hard. Nobody ever said anything about my speech at home. We talked about it but I could just be me without working hard on being better. My brothers never tease me about my speech and my mom and dad always tell me I am special and amazing. I love being home.

Last summer, I had my first sleepover at a friend's house for his birthday and I was so excited. My mom is so protective of me and my brothers so it was awesome she was letting me go. I was scared to be around his other friends because I didn't know them. As soon as I got there, they started asking me why I talked funny. One of them even started stuttering, just like me, and then they all laughed about it. I wanted to go home but I didn't want them to call me a baby, so I stayed. After a while I told them to stop and my friend's mom told them to stop, too. We watched movies and played video games and then went to sleep. The next day, they didn't say anything about



it again and my dad came and got me. I told him all about it and he told me how proud he was of me for sticking it out and not coming home, crying. I felt great about it too!

This summer my Mom took me to Arizona to the NSA Conference. I was so scared to go and wasn't sure what would happen. I had a few bad days at first when I met everyone and heard them talk like me. I was mad and scared and I just wanted to get away from everyone. I kind of feel bad about that now. I thought my mom or my speech teacher was going to fix me and it was just taking longer than I thought it would. Going to the conference changed that for me. I now know that I will always stutter and that it's ok. It was hard for me to accept that, but I do now. I'm not saying I'm happy about it, I'm just not that mad about it anymore. My mom says not to worry about something that I can't control, and that it is what it is. I think I know what she means now. I can't make my stutter go away but I can manage it by letting go of it.

Since the conference, I still have bad days but I have good days, too. I try to use my tools when I remember to but I don't when I'm home with my family. I can be me and don't have to explain it to them. That's how I feel about everyone in the NSA: it feels like family! ::

Kids  
CHAT