

Family VOICES

Celebrating 35 Years of
Changing the Lives of People Who Stutter

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*...for kids and
teens who stutter,
their parents,
SLPs and others
who support them!*

Stuttering from a Dad's Perspective

JOHN DANIEL, KENTUCKY



The thought of discovering that my child stuttered was an eye opener and heartbreaking at the same time. I remember the day I found out from the doctor that J.D. has a stutter. I quickly researched the topic and discovered there wasn't anything I could do from a medical standpoint. So, I cried, prayed, and eventually accepted J.D. and his stutter for what it truly is; it's J.D. and it's what God wanted for us to accept as a family. Everything J.D. does warms my heart, whether he believes that or not. I know that, speech-wise, certain things are difficult for him but I see that he's mature beyond his age in other areas of life. A great deal of this maturity has stemmed from our annual trips to the NSA conferences. I truly believe that this helped not only J.D. but our entire family. Our first trip was especially helpful and emotional for me. I'm grateful for the conference and for what it has done for our family.

I'm a Police Officer in Louisville, KY. In my line of work, I see people from all walks of life. Some are good and some are bad. There are times in my profession when I see kids take their speech for granted and that spills over into daily life. When I see these kids making fun of someone for their

speech it hits home. I've attempted to educate these young men and women on their action and words, and let's just say, I've received "mixed" responses from them. It's hard to change one's lifestyle from the streets in just a quick counseling situation. I'll continue to speak out to anyone that bullying someone for their stutter is offensive and cruel.

I'm proud of my son for not only what he's accomplished so far in life but what he WILL accomplish the rest of his life, with or without a stutter. I love you J.D.! ::

*J.D.'s Dad
John Daniel*

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Ask the EXPERT

JOHN TETNOWSKI, PH.D., CCC-SLP, BRS/M-FD



A recent parent study conducted by the NSA indicated that parents become less involved in their child's stuttering therapy and supportive therapy (practicing at home) as their children get older and become teenagers. The NSA's John Tetnowski, Board Recognized Fluency Specialist and Mentor and Chair of the National Stuttering Association Research Committee discusses some of the reasons this may occur and addresses parental concerns.

In my 20-plus years of clinical experience of working with people who stutter, I feel that I can add some clinical insights to the data that the NSA collected. The group of people that we are talking about (teens and pre-teens) can be particularly tough to work with, but the group that I enjoy working with the most. There are a few points that I think are really important:

1) Teaching is one of the most important roles.

The Speech-Language Pathologist (SLP) needs to work with the CWS (children who stutter) to help them understand what is going on. It is not just about *fluency*, nor is it just about *acceptance*. They must be educated about the whole process. Why it's tough to talk, why others might tease them, etc. I think that almost half of each session with kids this age is about education and getting their feedback.

2) The teaching role is also important with the parents. If we bring the parents into each session, we have taken away their child's responsibility. I gave this example just the other day at a conference. Therapy is like the middle school and high school science projects that we see. If the parents build most of the project, it looks great, but the teen has learned very little. The best learning occurs when the parents watch and help, but the teen builds the project by themselves. This promotes maximum long-term learning. This is the same with stuttering therapy. We need to encourage and help our teens, not just do it for them. Just to let you know, I have a 13-year old daughter myself! She does not stutter, but she has her own struggles, so I understand that explaining to a child or teen that they should do something for the sake of "it will do you lots of good" or "it's the right thing to do" or "do it because I said so" is not as simple as it sounds.

There is no *one* way to implement therapy with teens, but rather several components that should be part of

the therapeutic model, including strong relationship(s) between parent, child, and SLP. It is also important to recognize that stuttering will have an impact on your child's life. They will be teased, they will be less successful at some tasks temporarily, and they may need to be **STRONGER** than they would have to be if they did not stutter. There is even some research that shows there is a "stuttering temperament," showing that PWS are more reactive to failure/teasing, etc. (Anderson, et al., 2003). We at the NSA see lots of positive examples of people who will get up and speak in any situation and succeed at it in spite of their stuttering. It is important to realize that they are the exception, and that it has not always been that way for them.

As you and your child work through this process, there will be many lessons learned along the way. Here is one of the best parallels from Walt Manning's text (2009) and he talks about stuttering and lessons learned from rock climbing (Note: The original parallels were provided by a 14 year old!).

Treatment generalizations (from "*Lessons Learned During Rock Climbing*" Manning, 2009, p.409)

- You have to learn... then practice.
- You have to take on more responsibility.
- You have to trust the other person.
- Effective communication is essential.
- You have to conquer your fear.
- It's OK to make mistakes.
- It's OK to get frustrated, eventually you will get it.
- It's OK if you fall.
- If you fall all the way down, start over again.
- When you're facing the edge, have faith in your support.
- You just have to find the right rocks.

SLPs are important here, and along with parents and NSA groups act as the support mentioned in the second last statement. We need to build up our kids, but help them to remember that "It's OK to fall." We should expect the SLPs to be the guides that help kids and parents to find the "right rocks" mentioned in the last statement.

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For more information

Anderson, J. D., Pellowski, M. W., Conture, E. G. & Kelly, E. M. (2003). Temperamental characteristics of young children who stutter. *Journal of Speech, Language, and Hearing Research*, 46, 1221-1233.

Manning, W.H. (2009). *Clinical Decision Making in Fluency Disorders* (3rd Edition). Clifton Park, NY: Delmar.

A New Outlook on Stuttering

ALEXANDRA D'AGOSTINO, ONTARIO, CANADA



During the summer I attended my very first conference of the NSA, and I had no idea what to expect. I found out about the NSA through my speech pathologist just this year, and now that I have been to the conference I wish I had found out about it sooner. I live in Ontario, Canada, and in the city that I live in you rarely hear the words “stutter” or “speech problem.”

Before the conference I had met a few people who stuttered through a program at our local university, but apart from that I thought I was alone with my stutter. I thought

very few people experienced this, and that it was just a fluke that I happened to be experiencing this problem. When I heard about the conference I couldn't fathom that that many people in the world could stutter like me. I was anxious and excited to go and I was even counting down the days! As soon as I arrived at the conference my thoughts and views changed. I heard people stuttering openly, and loudly too! There were so many people of all different ages, I had never heard adults stutter and I began to see them as my role models; the confident and extroverted person that I wanted to become.

My stutter started when I was 7, and as I grew up, I faced the harsh reality of bullying, and facing the fact that I was different. I grew more and more shy, quiet, and concealed. I was never myself when I was with my friends, at school, with strangers, or anywhere outside of my home. When I was at home with my parents I was as loud as could be, I felt like I could be myself and not have to hide my stutter.

This all changed in Grade 8 when I finally realized that I should not care what other people think about me. If people wanted to call me weird, different, ugly, make fun of my stutter, or insult me in any way then that was their problem, not mine. That year I became more confident in myself, and my stutter even im-

proved, but high school was a whole different story. I was still maintaining my motto, “Don't care what other people think about you,” but now I faced different bullies, drama, and the people who turn on you even though you think you are friends, and my stutter worsened. I've been able to stay true to myself despite all the pressure that high school brings, and now that I am in my last year of high school I still face those troubles, but with a new face. I have been spending years trying to hide my stutter, because I was ashamed of it. The NSA conference taught me that it is okay to stutter openly, and that I CAN be myself outside of my home.

Being at the conference gave me more confidence to stutter openly at school and in my community. Now I am auditioning for roles in musicals, writing blogs in my community, raising my hand in class, leading groups, and even ordering for myself at restaurants. Because I've been more open with my stutter, I've had a few interesting encounters with some people. One of them was when I went to the annual fair with my friends, and I had to ask for a general admission. Of course I stuttered and the man, who was elderly, told me that “I get in for free because I am handicapped.” I tried to explain to him that I was not handicapped and that nothing was wrong with me, but he just waved me through! I was absolutely shocked because before that I had never been classified as “handicapped”!

One thing that has gotten me through everything in my life, including my stutter, is music. Music is something that is so important to me, it is something that is not affected by my stutter, and it is basically my life! I have been playing the flute since Grade 7, but I also play 3 other instruments, I sing, and I am in almost every music ensemble at my school. I really hope to study music in University next year, and one day I hope to study at Juilliard in New York. ❖

Phoenix, AZ Youth Day

KAREN KUMAR, ARIZONA



The Phoenix Metro Area NSAKids & TwST group held a Youth Day on Saturday October 22 at Arizona State University in Tempe, Arizona. The Youth Day was attended by over 62 people including 34 adults, 9 children and 9 teens who stutter and their 10 siblings. After the opening words, the group played the “Three Words” video made by SLP Nina Reardon Reeves.

The NSAKids group made a Youth Day banner with personal affirmations and thoughts about stuttering. The group made an “I Can” man from aluminum cans, connected by a string, and the kids put strips of paper with “I can (fill in the blank)” in the man. The group also used a problem solving triangle to plan a cookie decorating activity.

The teen session used the recent New York Times article about a teen who struggled with a teacher’s response to

his stuttering in the classroom as a platform to discuss problem solving techniques. Challenges at school were familiar to everyone in the group so discussion was lively and the participants generated many ideas for working with teachers. Each teen created a problem solving worksheet for a situation of their own and everyone had a great time networking with others in the group. The groups was fortunate to have some fabulous young adults/college students help facilitate discussion and brainstorming and many valuable connections were made with new friends who also stutter!

The parents participated in a session that reviewed research and problem solving approaches to use with kids. The families participated in a panel discussion with six adults who stutter. Scott Yaruss led an interactive session on bullying and teasing.



Cincinnati, OH TwST Chapter

The Cincinnati TwST Chapter met with a total of 6 in attendance: a member of the Cincinnati adult chapter and a co-leader who brought along his son, the other co-leader, and two teens. One of the teens has never been to a NSA conference, so we attempted to explain to him what a conference is like and what the NSA is all about.

Our discussion was about making and achieving goals. Fluency Friday was the previous weekend in Cincinnati and the time right after a program like Fluency Friday or the NSA Conference is the best time to set goals, while you’re still feeling the direct after effects (high self-confidence, etc.) from it. We each filled out a worksheet listing one goal for ourselves (speech related or not) and then went into detail about how we will achieve that goal, when we want to achieve it, how we will know when we achieve it, and what is holding us back. We all shared our goals and plans and received feedback and encouragement from each other. Our goals included getting a new job, getting into graduate school, growing a business, speaking out more and talking to girls, and even going to The Cheesecake Factory! Next month we plan to update each other on the status of our goals.

Fort Worth, TX Family Chapter

Last month’s meeting had four SLP volunteers but no families, the time was spent planning how to increase attendance. The plan is (with assigned tasks divided):

1. Make the activity so fun the kids beg to go.
2. Redo the flyer so the topic is listed but the fun activity is highlighted.
3. Get the flyer to more SLPs.
4. Get the flyer out earlier, have more reminders, and call the previous attendees.

For this month, the leaders chose pumpkin decorating as the fun activity. ‘Flyer duty’ was given to the most artistic and computer savvy member. The bilingual SLP-Assistant then translated the flyer into Spanish, since the group is located in a minority majority school district. The flyer was distributed via the lead SLPs emails, and the lead SLPs in turn give it to all their district SLPs. The group also has plans to contact the local media, including local Spanish media.

This month, the kids got in groups with parents and other kids and talked about how to decorate the pumpkins. Then everyone got together as a large group and each child told something special about their pumpkins and/or themselves. EVERY child spoke in a rather large group of about 9 parents,

NSA Family Radio Schedule

Your Virtual Family Chapter for Parents, Kids, and Teens!

NSA Family Radio Shows are a HIT! NSA kids, teens, and parents are catching on to this form of virtual support which fills a void for families who can't physically make it to a support group in their area. Listeners can choose to be a silent participant or to contribute to the conversations.

Moving into 2012, there will be one show per month with a mix of hosts and topics. Show dates, times, and details are continually updated on our website. Teens who stutter, parents, experts and other special guests will discuss such topics as:

Wednesday January 18th 9PM EST: Teen Show

“New Year’s Resolutions” Making positive changes; What do we want to change? How can we do it?

Wednesday, February 22nd 7PM EST: Parent/Family Show

“Therapy” When to pursue therapy. What to do when your child no longer wants to be in therapy. Introduction to therapies for young children who stutter.

Tuesday, March 20th 7PM EST: Teen Show

“Applications” College Applications/ job applications. How does your attitude about your speech reflect your character on applications and interviews? Guests will share some of the challenges they’ve faced in college interviews as well as in the job application process and how they addressed /overcame them.



evening with Pictionary using Thanksgiving and speech-related words, apple muffins, and turkey shaped cookies, but since the group was so small, everyone met and chatted in the same room. The discussion varied on everything from schooling (what the teens were interested in studying to what the SLP student was working on to what Vivian, Mandy, and Jean had studied and where) to the holidays to international travel. There was also a discussion on what the teens could expect from the NSA conference in St. Petersburg.

The group leaders are planning to hold the December meeting at a local pizza restaurant and make it into more of a holiday party setting. Pizza nights always seem to draw a lot of participants, so the leaders have high hopes that this will get the attendance back on track! ::

6 children who stutter, 7 siblings, 5 SLPs, 4 SLPs’ family members, and one stuttering researcher. One family was Spanish dominant.

Afterward, the leaders received this email from one of the parents (who gave permission to share):

Thank you so much for putting this group together. Our son had such a good time on Tuesday and can't wait to come back. Normally he never talks about stuff but even brought it up again last night on how much fun he had. Thank you so much for putting in the time and effort to put this together each month.

Louisville, KY Youth Day 'Lifting the Weight'

On October 22, 2011, Louisville, KY hosted its first Youth Day. Miranda Smith and Jason Faust did an awesome job talking to the kids and playing “ice breaker” activities. Pam did a great job with registration. Brittany, as usual, was inspirational to us all, especially the kids. It was a phenomenal day for the kids!

Many participants stayed the night in Louisville at a local hotel. At the pool that night, the family that had driven 3 hours to attend the Youth Day unexpectedly walked in. The boys (who both stutter) recounted their day and talked about all that was presented to them. Their dad said that a weight had been lifted off of his shoulders. He said that he had always felt guilt about his boys stuttering, and that no one else in their family did. He thought that something he and his wife had done was the cause of it, and he worried that they would be limited in life. He also said that after the Youth Day event, he realized that the boys could do anything they wanted to, and that stuttering would not limit them. As tears streamed down this burly guy’s face, he said they will absolutely be at the convention this year.

Northern Virginia TwST Chapter

The Northern Virginia TwST Chapter met on Tuesday, November 8 with 7 people in attendance. The group was on break for the summer, and getting ‘back into the swing of things’ has been a little slow. The group continues to be led by SLP Vivian Sisskin, but co-leader Mandy Finstad has replaced the former co-leader Sonya after she moved out of state. PWS, NSA member, and SLP student Mark Baer also helps out in a leadership role. The November meeting consisted of Vivian and Mandy, Mandy’s (PWS) husband Jean (since Mark wasn’t able to attend), one parent, one SLP student, and two teens.

Typically the group splits up with Mandy meeting with the teens and Vivian meeting with the parents, and Mandy had prepared a Thanksgiving-themed

Own Your Stuttering

MATTHEW S., CALIFORNIA



Although I am slowly beginning to accept my stuttering, I have to admit that it is NOT my most favorite characteristic. Stuttering does make me different, even unique, but if I could get rid of it, I definitely would! Since I've been stuttering for as long as I can remember, it will probably be something that I will have to live with for the rest of my life. Because of this, I figured I should take some sort of ownership of it and make it all mine.

I decided to "own" my stuttering after a few people tried to take it from me by telling me how to speak, completing my sentences, or even making rude comments. So now I do my best to let others know that I am OK with my stuttering. This doesn't mean that it is always easy to talk about it, but I have found that I need to take charge of it or others will.

In the beginning of the school year, I was really bothered by two of my classmates who thought it was alright to laugh at the way I spoke. I let it go the first time, but I felt that I had to bring an end to it when they laughed at me a second time. Basically, I just told them that I stuttered and that is why I talk the way I do. I didn't go into a big explanation or anything, but it seemed to work as they haven't teased me since. At first I thought they were being mean, but maybe they just didn't understand that stuttering makes me speak differently than others. It's true that my stuttering can sound funny, but I want to be the one who laughs at my stuttering – not someone else!

After this experience, I realized that I needed to be more open about my stuttering and take the time to let others know about it. Recently, I have used several opportunities to inform my classmates about stuttering. For example, we had an assignment where we had to memorize a poem, so I decided to select one about stuttering. I have even given my teacher a couple of stuttering pamphlets so she would gain a better understanding of my speech condition. Also, I wanted to do

something special to celebrate International Stuttering Awareness Day so I gave my teacher the July-October issue of NSA's Family Voices and she read my article (*Stuttering: It's Not ALL of Me*) to the class.

Besides openly sharing and discussing my speech condition with others, I realize I need to "own" my stuttering in another way by working a little harder to improve my communication skills. I am starting to feel more relaxed about taking the time I need to manage my speech by using the different strategies that I have learned. In the past, I used to want to hurry through the words I got stuck on most often, but I found that approaching them more slowly helps me to speak more easily and with less tension overall. My confidence seems to increase each time I take back stuttering and stutter the way I want to.

Owning my stuttering is a process that I am still figuring out, but I can already tell that it feels good to stand up for myself. I am hoping that the older I get, the more comfortable I will become with my stuttering and that I will find it easier to open up about it. In the meantime, though, I know that I have to accept my speech one word at a time and do all I can to take complete ownership of my stuttering because if I don't then someone else will! ::

The Moving Man

CAM C., GEORGIA

Hi! My name is Cam and I have been stuttering since I was 3 years old. I am in 5th grade and sometimes feel like I am under a lot of pressure because of my stutter; let me tell you why. When I was in 3rd grade we moved from my hometown in Connecticut to Louisville, KY. Then in July of 2011 my family and I moved to Atlanta, GA. Moving two times in 1½ years is really hard, but when you stutter it can be even harder. I had to leave friends and family that just knew me as Cam, who happened to stutter, but didn't really care. It was a really hard time for me. I left my best friend and my extended family.

When I got to my new schools in Kentucky and Georgia, I was really worried about how people would react to my stuttering so my mom and I did a presentation about stuttering for my teacher and my classmates. I told them what stuttering is, what might cause it, and

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Young Journalists

Check out a few of the interviews that were conducted at the NSA's Fort Worth Conference this past July, at the 'Who's Who' letter writing workshop lead by **Alexa Jaworski** and **Jennifer Delaney**. Alexa is a PWS, writer, and English as a Second Language (ESL) teacher. She enjoys writing and has worked as a newspaper journalist for 10 years. Jennifer is a parent of a child who stutters and this was their first conference.

All of the interviews written by NSA kids will be in Family Voices throughout the year.

Interviewer: Dayna Dankis

Interviewed: Molly Flynn

Is this your first NSA Conference? No.

What grade are you in? 3rd grade

Where do you go to school? Vancouver, Washington

What are you favorite activities or hobbies?

Dance, art, swimming

What do you want to be when you grow up?

Dance teacher and dog groomer

Do you go to speech therapy? No, I just stutter a little.

What would you like people who don't stutter to know about stuttering? I would like them to know that my brother plays guitar and likes pizza.



Interviewer: Grayson Nichols

Interviewed: Evan Tiller

Is this your first NSA Conference? Yes

Do you belong to an NSA chapter? Yes

What grade are you in? 7th, Austin Academy

What are you favorite activities or hobbies?

Read, video games, run

What do you want to be when you grow up?

Police officer or architect

Do you go to speech therapy? Yes

What would you like people who don't stutter to know about stuttering? It doesn't mean you have something

wrong with you.



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that I'm just like everyone else it just takes me a little longer to get my words out sometimes. My classmates really liked it and even asked me some questions. We talked about how everyone has challenges in their lives and this was mine. Then some of the kids shared things that were hard for them. But even though I do a presentation sometimes I worry that kids I've just met are thinking "What's up with that new kid Cam? He sounds weird." It also makes me worry that when developing friendships with new people they'll think my stuttering is really weird, so sometimes I'm really careful about what I say so I don't stutter as much.

I also like to play sports, especially baseball, and that helps me meet new people and because we are all doing something we really like people don't really pay too much attention to my speech. One thing that is hard though when you're new is when a coach asks you what position you usually play and you stutter it sometimes sounds like a position that you don't like to play but you get put in that spot anyway.

And because people know that I love baseball I'm asked frequently who my favorite player is. My favorite player is Dustin Pedroia, but that can be really hard for me to say and it comes out as D-D-D-D Dustin P-P-Pe----drioa. That can be very stressful.

If you are new to a school, you have to reach out to people even though you may be worried and it can be hard. You stutter, so what? Just be yourself, go up to people and introduce yourself. Once you do that your speech will not be on your mind as much. You will make friends. I did! I hope you enjoyed reading this! ☺



Freedom of Speech at the Beach

ST. PETERSBURG 2012

29th Annual Conference

Upcoming Family Events

February 25, 2012 | Tampa, Florida

Family Fun/Youth Day & Continuing
Education Seminar

March 3, 2012 | Kean University, New Jersey

Family Fun/Youth Day & Continuing
Education Seminar

March 10, 2012 | Orange County, California

Family Fun & Bowling Pizza Party

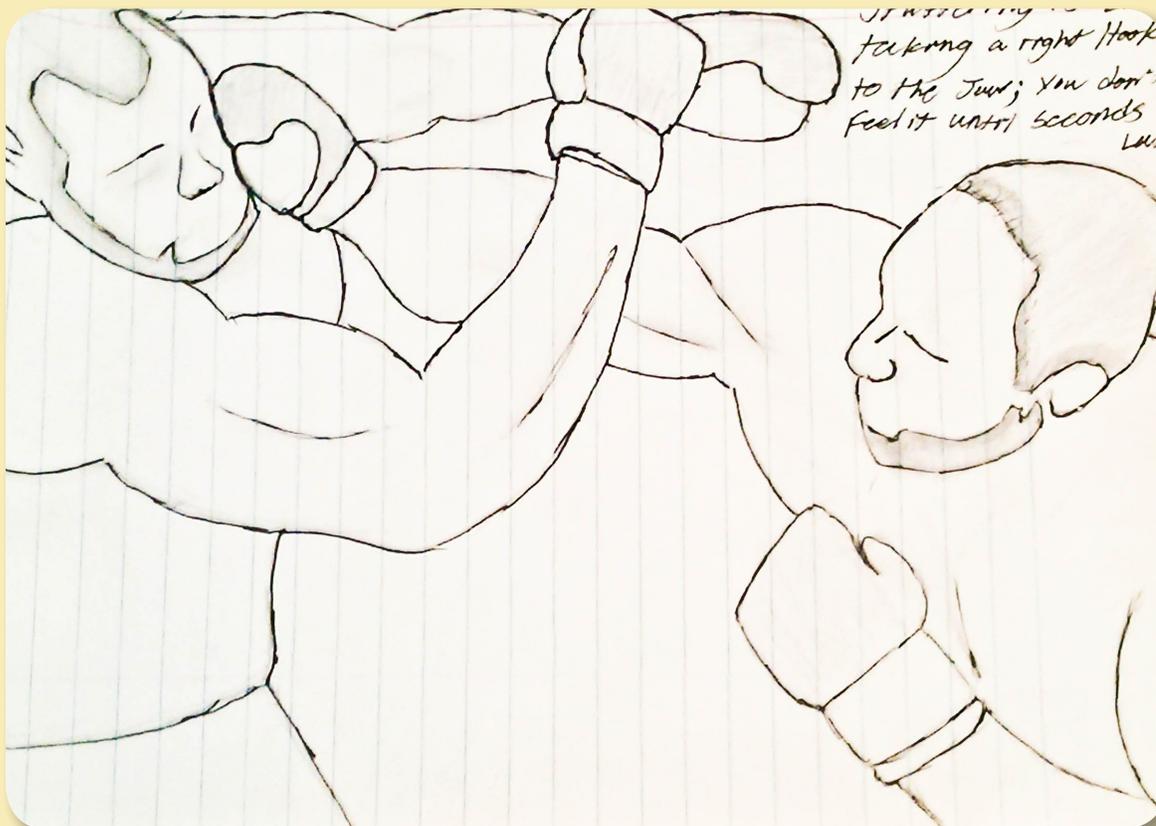
April 14, 2012 | Royal Oak, Michigan

Family Fun/Youth Day & Continuing
Education Seminar

July 4-8 2012 | St. Petersburg, FL

29th Annual NSA Conference

Please visit our website at www.westutter.org
for more details!



“Stuttering is like taking a right hook to the jaw; you don’t feel it until seconds later.”

.....

Braden Barber, Texas

Braden is a junior in high school in his home state of Texas, and also serves on our Teen Advisory Council. He has been a member of the NSA for 5 years, and has been on the Teen Advisory Council since 2009. Braden is active in helping his mom with the Dallas TWST support group, and enjoys mentoring and helping others by sharing his struggles with, and educating people about, stuttering. His future plans include the Air Force followed by a career in law enforcement.