

Family VOICES

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119 W. 40th Street, 14th Floor
New York, NY 10018
phone: 800.WeStutter (937.8888)
212.944.4050
email: info@WeStutter.org
web: www.WeStutter.org

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

Another Special NSA Moment

JOAN ROSS, NEW JERSEY



Fours year ago my family attended our first NSA Conference in our home state of New Jersey. My daughter Courtney was 14 years old at the time and had been stuttering since the age of six. In my heart, that first conference will always be my favorite. It was there that we met the greatest of friends on that first day and by the time that conference was over we were saying good-bye to family.

Four conferences later, and each year I watched my daughter grow stronger, healthier and more confident. But as much as she has grown over the years with the NSA, she still would not speak at the conferences. She still did not have a voice. She would rather remain silent than let anyone see her stutter, even in the one place where it was okay to stutter. I hoped and prayed that this would change in time. So when my daughter decided to join the Teen Advisory Council (TAC) this year, you can imagine my excitement as I quietly thought *maybe, just maybe, this will encourage her to speak*. In the days before the Fort Worth conference I worried and I wondered how this was going to play out for her as I listened to her worries.

Once we arrived we realized that they are not kidding when they say things are bigger in Texas!

Was it the state? Was it the fact that Courtney had joined the TAC and knew that that came with responsibility? Was it the love and the support that she felt year after year from her NSA family? Maybe it was the fact that this year at the conference she turned 18 or maybe it was all of the above and more! I'm not sure what it was, but I do know that this year my daughter flourished! She started out slow, but a few days into the conference, Courtney shined. She spoke, she shared, she laughed, and she cried. She was amazing! But most of all I feel as though she started to accept. Accept who she is, and accept that stuttering is just a small part of that person. That smart, beautiful, amazing person who just happens to stutter.

So even though our first conference holds that 'favorite' place in my heart, my special moment happened in Forth Worth, Texas, when my daughter helped me to realize yet again that finding the National Stuttering Association was the best thing that has ever happened to our family. We are all so proud to be associated with one of the greatest groups of people in the world!! ::

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Ask the EXPERT

VIVIAN SISKIN, MS, CCC-SLP, BRS-FD

Q: My 14-year old son has been going to therapy for stuttering and they are working on things that don't seem to directly relate to his speech and helping him to control it. They are not "practicing and using tools". The SLP talks about peeling back the layers. What does this mean and is it really going to help?

A: Avoidance and concealment behaviors associated with stuttering are like the layers of an onion. As you shed one, another is revealed. For many school-age children, the stuttering pattern has become extremely complicated in just a few years. Word substitutions, use of fillers such as "um", and even silence now mask a simpler form of stuttering, present at a younger age. But, in order to understand *why* and *how* clinicians help those who stutter peel away the layers, it is helpful to understand how the layers were formed to begin with.

Disfluency in very young children is often easy and forward moving. Sometimes there is no awareness, and no struggle beyond momentary frustration. However, stuttering behavior changes over time as children discover strategies that "work" (at least temporarily)

by helping them escape from shameful or annoying speech. The desire to escape negative listener reaction (or the fear of potential negative listener reaction) is the most common motivation, but frustration and impatience in getting through a block can also motivate escape. Children discover, sometimes by accident, that a novel behavior will

release the block. These reactive behaviors become conditioned responses (habits) that define the stuttering pattern for that child.

While many reactive behaviors (sometimes referred to as secondary behaviors) were originally learned to hide stuttering, and continue to serve that function, they don't always do a good job anymore. The child often struggles on the very behavior once used to hide stuttering. Below are some examples:

"My name is (tense pause), my name is (tense pause), my name is Sam".

Here, a phrase is repeated over and over until the child can say his name without blocking. The phrase repetitions serve to mask the block, which would ordinarily occur on Sam.

"Do we have p.. (tension), uh, gym this afternoon?"

Here, both a filler word (uh) and a word substitution ("gym" for "P.E.") are used.

In some cases, when reactive behaviors hide overt stuttering well, family members think that stuttering has gone away. However, the truth is that the child is working very hard to conceal it. This takes a huge toll emotionally. The child feels very much alone in his efforts to hide stuttering at all costs. In other cases, the child may show overt struggle behavior on top of all of the layers. "Tools" are effective when the child makes a choice to use them for their intended purpose. If they are ultimately used as another way to hide, they will be ineffective in real life situations, and the child loses motivation to practice them.

Peeling away reactive behaviors in the course of treatment involves focused work. Reducing them often requires education, counseling, and direct work on attitude change. In order to shed these layers, the child must grow more willing to show stuttering rather than hide it, and must develop the confidence to believe that "it is OK to stutter." Parents can help by modeling tolerance and acceptance of overt stuttering as it is revealed. This process, called desensitization, is carried out gradually and systematically with the help of a skilled clinician.

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Vivian Siskin, MS, CCC-SLP, BRS-FD

Board Recognized Specialist - Fluency Disorders

Dept. of Hearing and Speech Sciences

University of Maryland

vsiskin@hesp.umd.edu



Tammy Flores and Vivian Siskin

NSA Family Radio

Your Virtual Family Chapter for Parents, Kids & Teens!

The NSA's Family Radio is up and running! Our first shows focused on the 2011 Annual Conference in Fort Worth, TX, and through August we aired our three part 'Back to School' series. Weren't able to catch those broadcasts? It's not too late! Head over to WeStutter.org and follow the links to the archived shows, as well as find upcoming topics and show times.

NSA Family Radio is hosted by the Family Chapters Committee of the NSA. The mission of the show is to bring together kids and teens who stutter and their parents, siblings and other family members in a way that is convenient from all over the world!

Stutter BUDDIES

Finish That Sentence!

At our 2011 Annual Conference in Fort Worth, Pam Mertz led a workshop for the NSA kids. During the workshop, each participant rotated through writing stations to complete sentences. Here are just a few of examples of what the kids had to say.



If stuttering were a car, it would be:

- ... black, because it is not seen at night but during the day it is visible.
- ... purple, because I like that color.
- ... a time machine.
- ... a car that Brett Favre would use to go to the Viking Stadium.
- ... a Porsche that was out of gas.
- ... a Honda, doors would be electric like stuttering.
- ... a blue car, because it is my favorite color.
- ... red, because it is pain.
- ... a white car, because I do not like that color
- ... a beetle bug, because they are cool just like stuttering.
- ... a Model T, because it would be slow.
- ... a truck, because it is so bumpy.
- ... white, because you hardly see it.
- ... a jeep, because it is bumpy.
- ... a limo, because it is big!
- ... a jeep, because it is awesome.
- ... a Ferrari.

At the 2011 Conference, I met a kid named _____ and he/she is really cool because _____.

- ... Zane, because he can do a handstand underwater.
- ... Carson, because he does not make fun of me.
- ... Joseph, because he understands what I am going through.
- ... Elly, because she doesn't care if my brother stutters.
- ... Aspen, because she is always so nice and is always there.
- ... Carlo, because he does not make fun of me.
- ... Brody, because he sometimes stutters.
- ... Kristen, because she is awesome.
- ... Ian, because he is LEGIT!
- ... Rylee, because she is my new friend.
- ... Carson, because he doesn't make fun of me when I stutter.
- ... Alexis, because she talks fast.
- ... Bella, because she is a GIRL!
- ... Mikey, because he can do a flip.
- ... Kyanna, because she can jump in the air and land in the splits!
- ... Noah, because he can run really, really fast.
- ... Olivia, because she plays the guitar.



NSA Teen Advisory Council Wants You!

The Teen Advisory Council (TAC) of the National Stuttering Association will be accepting applications for those wishing to serve on the Council in 2012 starting October 1st. All applications are due by December 1st. For more information on the TAC or on applying, please contact us at info@westutter.org.

Tips for Family Chapters

Planning topics and activities is a big part of leading a family chapter. The NSA has a manual with ideas as well as resources in the leader area of the website. Cora Campbell, leader of the Los Angeles TwST Chapter, shared with us her plan for future meetings.

October:

International Stuttering Awareness Day, Oct 22 Disability Awareness Month

Ice Breaker: "M&M Get-to-Know You"

Have each person grab some M&M's. They can take as many as they want. After everyone has some candy, each person has to tell one thing about themselves for each piece of candy that they have in front of them. This game can also be done with pretzels or other small snack food.

Topic: "How to educate listeners about stuttering"

- Facts about stuttering
- What can listeners do
- Personal insights from teens
- Personal insights from parents
- Discuss the advice that should be given to parents of children who stutter

Closing game: "Utopia"

Come with pens and a big pad and have everyone participate in drawing a group picture. Then have each person share their experiences with the group. Who were the leaders and who the followers? Did people wonder what others were thinking of them?

November: "Giving thanks"

Ice Breaker: "Good News"

As members introduce themselves, ask them to add some good news from their recent experiences; something good which has happened to them recently.

Topic: "Are you thankful for your stuttering?"

- Why or why not?
- What are the best times and ways to advertise your stuttering? (Especially around holidays)

Closing Game: "Table Topics for Teens"

December: Holiday Party!

Topic: "Picture Party"

Have each member bring in a picture and explain it. Talk about favorite Christmas memory or this year's holiday plans.

Los Angeles TwST | Los Angeles, CA

The LA TwST Chapter had 5 attendees at their first TwST meeting, including Mike Lee, the Chapter Leader for the new TwST Chapter in Irvine who came by to observe how meetings are run. Attendees also included Andrea Maize and her 15-year old son, who had never been to an NSA meeting, but subscribe to the NSA newsletter.

Co-leader Josh Marcus helped to facilitate the meeting where participants discussed stuttering and school. Included in the discussion was:

Advocating and speaking up for oneself

- The importance of speaking and finding your voice
- Each person felt like they did speak up and participate in school

Families

- Families were supportive of those who stutter by giving eye contact, waiting for the person to talk, not interrupting, etc.

Most easy situations/Most difficult situations for PWS

- Easiest was talking to one's self, friends, and family.
- Most difficult was speaking in large groups (especially in professional settings), raising your hand in class (especially when everyone is really quiet), and speaking on the phone.

Lastly, we learned a little bit about each other

- Clay often travels and meets many people during his travels, making it easy for him to talk and be open with many people. Everyone really valued his confidence and perseverance.
- Andrea was really proud of her son and has been really supportive of him.
- Mike is a mild PWS and has a thirteen year old daughter who stutters. He was happy to be at the meeting and seemed to learn a lot, preparing for the TwST Chapter in Irvine starting on September 26th
- Josh equally participated and facilitated the meeting, as well as shared stories about school, family and the NSA Adult Chapter.

NC Triad

On Saturday October 8, 2011 the NC Triad chapter of the NSA partnered with a group of speech-language pathologists from Guilford County Schools to host the 2nd annual NC Youth Day in Greensboro, NC. The Youth Day was attended by 16 children and teenagers from 4 to 16 years old who stutter, 24 family members, 1 speech-language pathologist, and 4 speech-language pathology students. After breakfast and a formal welcome, 5 speech-language pathologists from Guilford County Schools led breakout sessions for the parents and children. The parent sessions included presentations and resources about supporting their child when dealing with bullying and teasing. A panel of 4 adults who stutter and 1 adult who clutters shared their journeys with the parents and answered questions from the parents about their perspectives on different issues surrounding stuttering. The panel was a favorite activity among many of the parents, and one parent remarked, "The personal stories were very inspirational." Several of the parents noted that what they enjoyed the most was sharing with other parents of children who stutter.

In the morning sessions, the children explored their feelings about stuttering by creating a stuttering collage, sharing what "rabbits" they pull from the magic hat to help with their stuttering, using play dough to express what their stuttering feels like,

and playing with different types of airflow with bubbles, balloons, bubble gum, and the belly button. After a pizza lunch, the older children role-played how to handle a bully, went on a scrambled egg hunt to learn myths and facts about stuttering, and wrote themselves letters that will be mailed to themselves in early 2012. Throughout the day, the children competed to see who could get the most stutter stars and won prizes at the end of the day for their stars. The Youth Day closed with an open mic session where the children were running excitedly up to the microphone to share with everyone what they had learned. One of the children shared that he had learned that “you don’t have to be afraid to stutter.” The children also showed off their “stuttering expert” badges that they had earned at the end of the day.

From the continuing education workshop for the speech-language pathologists to the breakout sessions during Youth Day, these events helped us all to become our own stuttering experts in one way or another. We have to thank the individuals and grocery stores that donated funds and supplies and the church that donated its facilities to support our event. We also have to thank the men who acted as panelists (Jason, Ronnie, Drew, Reuben, and Doug), our original “stuttering experts” (Reuben and Myrlene), and our facilitators (Matt, Lilli, Tonya, Ginny, and Emily) for giving their time and expertise to make our Youth Day such a success. ::



Farewell to a Fabulous 2011

Welcoming an Even Better 2012!

Family Programs has had a busy but incredibly successful 2011! We had 75 families attend the 2011 Annual Conference in Fort Worth, with 42 of those families attending as First Timers! The 2011 conference was our most successful to date, and we look forward to building off of that success as we begin planning for our 2012 conference in St. Petersburg, Florida. We are excited about the potential for next year’s conference as we strive to enrich and broaden the scope of Family Programs workshops and activities.

Family Programs is also excited about our new radio program, NSA Family Radio, which was rolled out in June 2011. NSA Family Radio is a virtual family chapter for parents, kids and teens, consisting of 2 shows a month, one for parents/kids and one for teens. The shows are hosted by parents, teens, and NSA staff, and are a great place to share ideas, information and provide support. One of the best features is that each broadcast is recorded and archived, so even if you are unable to tune in live, you can still listen and learn at your convenience. Be sure to check out our website for a list of upcoming shows or to check out a past broadcast.

We would also like to welcome our new Family Chapters Leaders and thank our “veteran” chapter leaders for all of the work that they do and for the support that they provide for kids and teens who stutter and their families. You touch the lives of countless families and selflessly give your time to help those who stutter, and we want you to know that it does not go unnoticed.

Lastly, Family Programs would like to thank all of our volunteers who give their time at the conference, on special projects, and serving on various committees. We could not do all the work we do without your support!

Best wishes for a wonderful holiday season and great 2012!

*Stephanie Coppen & Sheryl Hunter
Family Programs, Co-chairs*

Entering the Work Force as a Young PWS

CHRIS BURGESS, MARYLAND



In a recent post to the NSA Teens Yahoo! Group listserv, one of our younger members expressed a common concern regarding entering the work force, and expressed doubt that being confident and accepting of your stuttering could have an impact when trying to get a job.

As a young adult who has made his way through many diverse employments over the last few

years I feel it is important to mention that confidence in yourself and acceptance of your speech are the MOST important weapons when interviewing for employment. It helped tremendously that my first two jobs were acquired for me through family, but I quickly learned the harsh reality of the workplace and it's no nonsense environment. I have had almost a dozen jobs and countless interviews and I learned that it is not like school or home life where you can skip hard classes or bring notes from speech therapists to maneuver through tough situations. Your stuttering is a part of you and the people that care about you, need you, and understand that you have something to say that's interesting and important, will accept it.

Like many, I started on the bottom as a dishwasher/janitor and worked my way up over 5 years to become a sous chef in Baltimore. I trained countless cooks,

called out orders all day, worked as a delivery driver, and even manned the cash register and took phone orders on occasion, but I still can't say 5 words to my father without extreme blocking. As backwards and as frustrating as that might seem, we as stutterers need to understand that large components of fluency are environment, audience, purpose and confidence; rather than mechanics.

Although I never imagined being able to do these things prior to working, I was able to do so because I felt comfortable, confident, and in control. Now I'm a 21-year old father and full-time postal carrier. I was able to go through two grueling interviews and three weeks of intense training fairly smoothly because of the experience I had in dealing with job interviews and adapting to new work places. I know that entering the work force can be daunting but we all have to do it to survive, so we need to try our best and just know that even if we have trouble or don't get the position, there will be dozens of other opportunities.

One final tip: Begin the interview with, "I just want to start off saying that I sometimes have a stutter when I'm in nerve-racking situations (slight chuckle) like job interviews." Play it off as funny so that it establishes your stutter, breaks the ice, connects you to the interviewer on a personal level, and relaxes your nerves so you stutter less. Although 99% of interviewers and employers are open and understanding, it is still important to portray professionalism and assure them your speech is different when you are actually working and that they shouldn't expect problems with your performance. Get your foot in the door and deal with adapting to the job as you go. Good luck! ::

Upcoming Family Events

November 17–20, San Diego, CA

NSA will be at Booth 1826 at this year's ASHA conference, so head over and say 'hi'!

February 25, 2012, Tampa, FL

Continuing Education Seminar/4th Annual Youth Day

February 25, 2012

Orange County Family Fun Day
Orange County, CA

April 14, 2012

Michigan Family Fun Day and CEU
Royal Oak, MI

July 4-8, 2012, St. Petersburg, FL

29th Annual NSA Conference
www.westutter.org for more information

TAC News

SARAH D'AGOSTINO, NSA FAMILY PROGRAMS ADMINISTRATOR

As 2011 winds down, the NSA is proud to showcase the Teen Advisory Council (TAC) who have been working hard all year to make a difference in the lives of people who stutter. The group started getting to know each other over Skype last spring. They did a tremendous job helping to plan the teen workshops for the NSA's annual conference in July. At the conference in Fort Worth, they really got to shine as they lead workshops, made presentations for parents, spoke in front of the general session, and did their best to make each of the teens present (over 90 of them!) feel welcome. However, their job didn't end there! All of the TAC members have fall projects planned either online, in their communities, or in their schools to bring awareness to others about stuttering. Here is sneak peek at some of the things they have planned. Be sure to look for details on the website and in future newsletter!

Braden is creating an art piece that "speaks" about stuttering including his own photography and what each one means to him personally.

Miranda is hosting some of our upcoming NSA Family Radio shows for teens. (See website for details) She has also set up a fundraiser at the restaurant where she works, taking place on September 22nd, in hopes of raising money and advertising her local adult and teen chapters. She is writing an article about the fundraiser in hopes that local media will pick it up.

Courtney is working with her local NSA support group to get involved. She is working with the chapter leader to find a way for the group to put together a newsletter piece. She also has a ton of photos to contribute to the teen portion of the NSA website.

Shawn is giving a presentation on *Life with Stuttering* to one of the speech language pathology classes at his college (fluency class). He has also made great strides in being more open about his stuttering and he told everyone in his Accounting II class that he stutters. He never thought he would have the guts to advertise like that in front of 60 new people who he didn't know!

Garrett is working on a speech/project about stuttering at school, as well as assisting the Family Programs committee on several projects.

Ben is starting a chapter for teens who stutter (TwST) in Central Massachusetts. In the short term, he is willing to serve on the Family Programs Committee to help improve the NSA website.

Chloe is planning to spark more interaction on the NSA Teen Facebook Page. She is calling it "Conversations with Chloe...a Fall TAC project!" She will report back on how the teens respond to questions such as, "How do you guys feel about ordering food at a drive thru, talking on the phone asking, someone on a date/to a dance, stuttering and sports?" etc.

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To learn how to apply for TAC 2012, please visit the teen section of the NSA website.



Accepting My Stutter

DANIEL W, TEXAS

My name is Daniel and I am a high school senior from Houston, Texas. I attended the National Stuttering Association Conference for the first time this summer. I had a blast and learned so much. I learned how to accept my stutter the way it is. If I had a chance to make my stutter go away I would not make it happen because my stutter is what makes me the wonderful guy I am today.

I met lots of new people who really opened up to me. I never knew so many people stuttered. There were over 800 people at the conference. I am very happy with myself for accepting my stutter. I now don't worry when I talk to people. It makes it much easier for me to talk with others knowing that I might stutter or I might not.

I am very glad that I attended the conference because it really built up my confidence. It feels like home because you are around people just like you who understand how it is. Even though this was my first time to attend and I didn't know anyone there, I felt really loved and accepted. I didn't want to leave. I plan to attend the conference next year in Florida.

Thank you to everyone who made that possible for me!

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Daniel is 18 years old and an award-winning cellist. He plans to study music in college.



I Stuttered Out Loud!

TERESA HINEY, NEW YORK



A few months ago, I was fortunate enough to attend my first NSA conference. I found out about the NSA after seeing *The King's Speech* over Christmas break in Syracuse with my mother. I saw a table outside of the theater and was wondering who had set up shop there and what they were trying to sell, until I saw a poster that had the word "stutter" on it. I immediately rushed towards it. I met a young man from the Syracuse chapter, and I happened to ask him, "Don't they have a conference or something each year?" He confirmed that they did, and told me it would be in Fort Worth, Texas the following July.

A few months of planning and excited anticipation later, July 4th finally came, and my parents and I flew to Texas. Being my first conference and my first real interaction with other people who stutter, my nerves were on high. *"What should I expect? What will we do? What will the other people be like? Will they stutter like me?"* 5 days, 8 new phone numbers, about 6 workshops, and a countless number of new friends later, you could not have dragged me out of Texas. I thought worriedly, *"How can I go home now? I do NOT want to go back to fluent people. How am I supposed to go back to work now? I do not want to go back to the real world!"*

Being a first-timer, I was asked by many people what I thought about the conference. That was easy – I loved it. But back in Texas, I had no idea what to do with all this new information and new emotions going on around me. I knew the conference was a good experience for me, I just did not know *how*. Knowing that, I wrote a list on my red-eye flight back to New York about everything I had learned while at the conference. There was no other way to organize my thoughts. The number one thing that I finally learned, after 10 years of stuttering was: It IS okay to stutter. There were about 800 other people who stutter there with me. I was okay, we all were okay.

One thing that hit this idea home was a phrase I wrote down from David Seidler's keynote speech. In the speech, he claimed, "I am who I am, internally." After hearing that I recalled what other people at the conference had said; they said that we are not defined by our stutter, it is *part* of us, not *all* of us. I am more than my stutter. Another thing I learned was that the specific troubles that I face, face other people who stutter too.



I remember talking to a couple, Brandon and Dawn, one night at the hotel a day or two after the conference had finished. Brandon told me a story about how he had gone through the drive-through of a fast food restaurant, and being someone who stutters, he did not want to speak so he had the person in the passenger seat next to him yelling the order over him. Until then, I thought I was the only one who had such a ridiculous experience. I then told him about how when I was in driver's education in high school, my instructor made the driver (who was unfortunately me at the time) pull into McDonald's and give the orders of the four other people in the car. Of course my enemy sound being *M*, the irony that I had to order an M&M McFlurry and medium fries was not lost on me. I thought I was the only stutterer who hated drive-throughs!

After the conference, I stuttered out loud. I was more open about my stutter. I even became more talkative at work. I would order items at restaurants and coffee shops and stutter to a complete stranger. Prior to this point in my life, I would have been devastated by these public dysfluencies, but now I accept them, and was even proud of myself after they happened. The conference gave me friends, confidence, knowledge, and an even greater acceptance of myself. The difference is not necessarily in the workshops, or the scientific information you are given about stuttering, but rather in the people, the ones you meet and even the ones you do not. The immense and impossible amount of patience, camaraderie, and understanding changed me for life. It was quite literally the best time I have had in my life. ::