

National Stuttering Association

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

family Voices

Hello Friends!

by Sheryl Hunter and Stephanie Coppen



National Stuttering Association

Changing the lives of people who stutter

As the new co-chairs of NSA Family Programs Sheryl Hunter and I (Stephanie Coppen) would like to take this opportunity to introduce ourselves.

Sheryl is mom to Logan, age 7, and I am mom to Cam, age 9. We all met each other about 1 ½ years ago at the Tampa Youth Day in Florida. Sheryl and Logan are from the Tampa area and Cam and I flew in from Connecticut because we were not going to be able to attend the 2009 conference in Arizona. Cam and Logan got along rather well and Sheryl and I had the chance to get to know each other a little.

We exchanged emails and over the last 18 months we have kept in touch. During that time, Sheryl and I have become more and more involved with the NSA and are now honored to serve as co-chairs on the Family Programs committee. We have relied on, and been supported by, the NSA and its valuable information and resources. We have also received amazing support from other parents that share the same concerns, fears and triumphs that we've experienced with our kids.



Sheryl and Logan

We are off to a great start! We're in the early stages of developing new and creative ways to best serve



Stephanie and Cam

your needs. As these programs and procedures are implemented, we will share them with you and look for feedback on how we're doing. You are our partners and the NSA family programs cannot be successful without you! Please feel free to contact us at anytime with questions, concerns or feedback.

We would also like to take this opportunity to talk about the start of the school year. It's hard to believe that summer is winding down but before long the kids will be back at school. The start of school can be a stressful time for everyone, but especially for children who stutter. Talk to your child about how they would like to discuss their stutter with their teacher. Do they want you to have that conversation, would they like to speak to the teacher with your help or would they like to handle it on their own? Perhaps your child would like to give a presentation to their class about stuttering.

We have found that if classmates have information about stuttering it becomes less of an issue. Be sure to visit the NSA website www.westutter.org for back to school tips and brochures that you can pass along to your child's teacher(s). There is great information available that you will find helpful.

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119 W. 40th Street, 14th Floor, New York, NY 10018
800.WeStutter (800.937.8888) • 212.944.4050
info@WeStutter.org • www.WeStutter.org

Ask The Expert

by Craig Coleman, M.A., CCC-SLP, BRS-FD

Promoting Individual Differences



Children who stutter may exhibit a variety of reactions and emotions associated with their stuttering. Many of the negative reactions that children can develop stem from a feeling of being “different” from their peers. Instead of viewing their differences as flaws, we (speech-language pathologists, parents, teachers, etc.) need to help

children embrace their differences as part of their individuality.

By discussing individual differences, we can help children see that stuttering is simply one way that people may be different from others. Children can wear glasses or braces. Children can have allergies, asthma, or diabetes. Children can use a wheelchair or crutches. Children can have red hair, blonde hair, or black hair. Children can stutter.

Speech-language pathologists and teachers can educate students and their peers about individual differences to help ensure group learning of this important concept. Classroom presentations or activities to highlight diversity and differences can go a long way in fostering acceptance. Teasing and bullying often arises from a lack of understanding of individual differences, or in reaction to negative thoughts about one’s own self-worth. Helping children understand the value of diversity can underscore the importance of accepting things that are different about our self and others.

Parents can discuss individual differences within the family and explain how these differences all bring value to the family and help shape who we are. As someone who has never stuttered, I can personally speak to the lessons learned from being fortunate enough to meet new people who stutter on a daily basis. In partnering with the children I work with, and their families, I have learned to embrace individual differences, rather than try to fit them to a certain expectation. I have also learned the importance of being who you are, rather than simply who or what others want you to be.

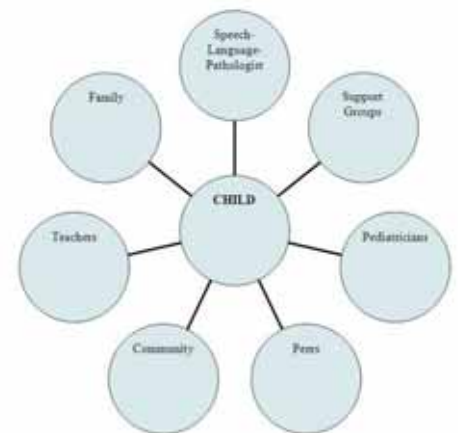
Creating an environment of acceptance is important for any difference, but particularly so for stuttering. If we place value only on fluency, we may lose the ability to promote an environment of acceptance. Placing too much focus on fluency can lead to children equating fluent speech with “good” communication and disfluent speech with “bad” communication. In reality, fluency is only one part of communication. A speaker can be completely fluent but have a negative communication experience because of factors such as content, pragmatics, or avoidance. On the other hand, children can stutter and still be highly successful in their communicative interactions.

At the 2010 NSA Conference in Cleveland, I had the opportunity to spend an afternoon with the children discussing individual differences. It is always amazing to see the instant support that children who stutter get simply from being around other children who stutter. There is tremendous power that comes with feeling as though others have an inherent understanding of your differences, and thus you will have an inherent acceptance.

In Cleveland, I had the opportunity to read *Tarby Comes Out of His Shell* (Coleman & Weidner, 2009) with the children. Following the story, children were asked to write down one way that they were different. While many children wrote down that they were different because of their stuttering, some identified their differences as “liking music,” “eating a lot,” “having a lot of muscles,” or “having a brother who stutters.” This variety is exactly what one would hope for when leading a discussion about individual differences. Stuttering is just one thing about a person that makes them who they are, much like their taste for music, preferences for certain foods, or body shape.

Having carried out this activity many times in individual treatment, I can say that the reaction among the children at the NSA Convention was much different. The sense of empowerment that these children displayed from having been around other children who stutter was phenomenal. It speaks to the value of partnerships between support groups, speech-language pathologists, parents, and children who stutter.

As such, the following diagram demonstrates the core components of how we can effectively view stuttering “treatment.” It cannot simply be a relationship between the child and speech-language pathologist. Effective treatment will help children navigate their relationships with all people involved in their lives, and help establish their communication roles within these contexts.



As a society, we have much work to do in accepting individual differences, but we have come a long way through education, awareness, and discussion. These are essential tools in creating a community where children who stutter do not feel isolated or helpless. It is up to all of us to continue to advocate for them.



Craig Coleman & Mary Weidner work with the kids at the 2010 NSA conference.



NSA's Rockin Conference Highlights!

The 2010 NSA Conference was a real success. Kids had a blast, parents learned invaluable information and teens were empowered by each other. These pictures are worth a thousand words.



EXPERT EXPERTS - A Terrific Panel of PWS SLPS by Caryn Herring

Stuttering had always been a non-discussed topic in my family. Although my family and friends knew that I stuttered, no one felt comfortable discussing it. The avoidance of the topic made me feel that stuttering was something that should be hidden, and that it was not appropriate to talk about how stuttering made me feel. I had the opportunity to co-lead a family workshop, with a panel of people who stutter, at the 2010 annual National Stuttering Association's conference and it was heartwarming.

The room was full of parents of children who stutter, eager to learn about stuttering. They seemed captivated as each co-host shared their story and they were then open to sharing their own experiences and asking questions. One father raised his hand and asked the panel what types of speech therapy they had received and what works best. It was touching to see that he wanted what was best for his son. He was clearly concerned for his son's future, and I feel that with the panel's responses we were able to ease his fears.

Being a part of this workshop, and speaking with parents of kids who stutter, reminded me of the importance of the NSA mission to bring people who stutter and their loved ones together.

It was eye-opening to see how involved these non-stuttering parents were in the stuttering community and to realize that their children will grow up in an accepting environment. Given the open communication within these families, I have confidence that the children who stutter will be comfortable with their speech and themselves from a young age.



NSA Teens-Smiles Say It All!

Conference highlights written by Sarah Onofri

Teens: Are We Having Fun Yet? (Games & Crafts)

For this workshop, we started out by playing "Two Truths and a Lie". Then everyone broke out to do whatever activity they wanted. Some people choose to play some of the games that were set up; nerf guns, hillbilly bean bags, putt putt and some made crafts while others just hung out. Chloe and I were in charge of crafts and to our surprise, our craft table was super popular. Most of the time, the table we were sitting at was pretty much full and people were making lots of friendship bracelets and different jewelry. It was a really chill workshop and a good time to just time to hang out and get to know the other teens.

Teens Advertising

I introduced the idea of "advertising"- where you disclose to your listener that you stutter. We talked about the benefits of being open. Then asked people what their thoughts and experiences were with advertising their stuttering. It was really interactive!

Parents Meet the TAC

This is a workshop that could last for hours and parents would still have questions to ask the TAC. Parents seemed comfortable enough with us to ask plenty of questions and seemed to get a lot out of it.

NSA Kids' Camp

NSA Teens had the opportunity to mentors the kids at this conference on Friday morning at the NSA Kid's Camp! It was a blast while they played games, sang songs, made s'mores and crafts, and got quality time together.

Teen Ice Breaker & Open Mic

After introductions, Stephanie Nicolai and I led the group in HUMAN BINGO! This game required everyone to mingle and move around, asking different people whether they fill certain categories (is a vegetarian, has driven cross country, etc.). Everyone there was really good about just getting up and getting to know everyone else. Then the group sat in a big circle and gave everyone the opportunity to speak and share whatever they wanted if they felt so inclined. Sometimes when there had been a silence, Stephanie would bring up something related to stuttering or ask some sort of question to get people talking again. It seemed to go really well, as people shared lots of different stories and it was just super chill and informal.



Greetings from Connecticut

by Tyler P. of Oxford, CT

Dear Stutter Buddies,

I will tell you my name. It is Tyler. I am a pretty funny guy. I stutter like you.

Have you heard of a DS? It's an electronic device for video games. I have one and it is truly awesome.

I don't know if any of my relatives stutter. If you struggle with talking, you get me, congratulations!!



You NSA Kids ROCK!

Take Your Time

by Dakota D., Mexico, NY

Dear Stutter Buddies,

My name is Dakota D. I am ten-years old, and I live in Mexico, NY. It is an awesome little town east of Lake Ontario. We get a lot of snow there. I have two younger sisters, a dog, and two cats. My hobbies are baseball, soccer, football, and basketball.

I've been stuttering for seven years. Stuttering makes me feel mad, but it doesn't get the best of me. I keep going when it is hard. Talking at a slower pace and restarting my sentences are two strategies that help my fluency. It also helps to have friends who do not pick on me. Once in a while, a kid will pick on me, but I let my teacher know and she takes care of it. Kids who pick on people are not the type of kids you want to be friends with. One of my favorite therapy activities is calling my old speech teacher from the elementary school and practicing my telephone skills.

If you give up, the stuttering will win. There will be good days and bad days, but if you slow down and take your time, your stuttering will improve.



Stutter Buddies

Stand Up for Yourself

by Nora, Richmond, VA

Dear Stutter Buddies,

My name is Nora and I am seven years old. I live in Virginia. I have one sister named Hannah and she is 9 years-old. I have one brother named Owen, and he is 4 years-old. I am in a class of first and second graders, and I am in first grade. I have stuttered since I was two. I didn't know that I stuttered until I was maybe 5 and still in preschool. It felt normal then and it still feels normal now. I have been teased tons of times, not about stuttering but about other stuff. Sometimes it is fun to be teased about funny things, but not about stuttering or anything else that's rude. Now, I want to tell a story about when I was teased about stuttering.

It happened in P.E. class. Everyone was talking about snow. It was really rainy so we were inside. It was the beginning of P.E. class. I stuttered on the word, "snow." Three boys teased me by mimicking how I said snow. They were talking about me to each other and I could hear them. I felt sad. It made me feel good when three of my friends, Jade, Eliza and Eiley, told the boys to stop teasing me. But the boys kept teasing until the girls said, "Stop teasing Nora" three times. Then I felt okay. That afternoon, I told my mom the story and she suggested that I write a note to the three boys that teased me. She helped me write it. I forgot what it said, but it worked. I brought the note to school the next day and gave it to one of my teachers. After she looked at it, she talked to the three boys with me. That made me feel better. My mom and I also decided to give a presentation to my class about stuttering, that same week in the afternoon. Everyone listened to her. It felt good. The boys wrote me a note at school to apologize. They haven't teased me again since then.

If one of the boys did tease me again, I would say "Stop! This already happened and I didn't like it." If I heard them tease someone else, I would say "Stop teasing them!" It feels bad when you are teased.

I learned that it feels good and is okay to ask for help. I learned that it is not okay to keep your feelings inside.

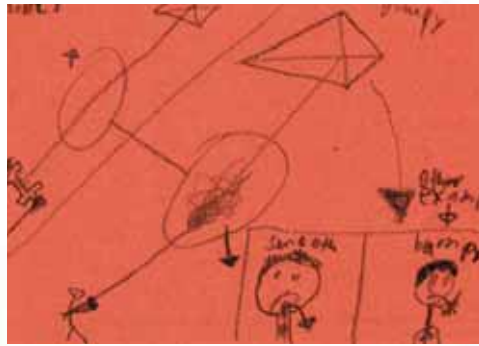


Wasatch Speech and Language Center in Holladay, Utah held a stuttering camp for children who stutter, ages 5-11. One of the activities asked the children to draw a picture of what stuttering feels like to them and how it makes them feel.



"A special thank you to the 2010 conference volunteers. We couldn't have done it without YOU!"

Arlene Truitt, Becca Liben, Bonnie Weiss, Braden Barber, Brandy Flores, Caroline Pittard, Caryn Herring, Cathy Olish, Chloe Whittacker, Christina Lapeus, Craig Coleman, Debbie Nicolai, Diane Games, Drew Kiser, Emily Callanan, Evan Sherman, Hayley Arnold, Jay Jones-Doyle, Jaelyn Reske, Jayna Rupp, Jeff Olevson, Jenny Padden, Joan Duffield, Joel Korte, Joseph Diaz, Josh Denault, Julie Raynor, Karyn Kovacs, Kathleen Kronenwetter, Kristen Pelczarski, Kyle Colen, Laura San Martin, Lauren Masuga, Lindsey Kodramaz, Lizi Pini, Lynne Remson, Margaret Duff, Marilee Fini, Mary Weidner, Marybeth Allen, Megan Berning, Michelle Coggins, Nina Reardon Reeves, Pam Mertz, Patrice Nolan, Pattie & Kayla Wood, Phil Garber, Phil Schneider, Rueben Schuff, Sarah Bryant, Sarah Mohl, Sarah Onofri, Sean Ridder, Shannon Beaty, Sindy Liben, Sonya Worosz, Stephanie Nicolai, Stephanie Coppen, Taro Alexander, Tess Dowgiallo, Tom Robert Scharstein, Vivian Sisskin, Kendall Kroner, Jessica Giuffre, Justin Spohn, Phil Temme, Matthew Capps, Jocelyn Robertson, Rachel Glasior



Jacob B. (age 7)
"Sometimes my speech make me bumpy and other times it makes me smooth."



Noah C. (age 11) *"When the string is tangled, like my speech, the kite goes down, but when its not tangled it can fly. When I talk smooth my throat feels open, but when I don't it feels tight. when I am bumpy, it feels like turbulence in a plane."*



Brandon S. (age 7) *"This is a stretchy speech robot. He reminds me to use my stretchy speech."*



Michael L. (age 9)
"Sometimes I get stuck. I can't talk. Like a knot, it's hard to untie. But when I use my prolongation, it's smooth."

James S. (age 10) *"You have know idea what's going to come out."*



William S. (age 10) *"Whenever I stutter it feels like there's a locked door in my throat that's keeping out the words."*



Joseph F. (age 5) *"Sometimes I feel bumpy with my speech and sometimes I feel smooth."*

Audran S. (age 7) *"Stuttering Makes me feel kind of nervous so sometimes I don't like it."*

AND EVERYONE ELSE!!!

If you want to volunteer for special projects throughout the year, contact Sarah D'Agostino at sdowgiallo@yahoo.com.

Following Nora's Lead - A Parent's Perspective

by Kara L. Page Richmond, VA

Nothing distresses a parent more than seeing their child distraught over their sense of self. I recently experienced this when Nora, my 7-year-old, told me she was teased when she stuttered in school. Nora attends a progressive school in Richmond, Virginia, and has been a part of this community since she was 2 ½ and entered preschool. It is a place where community, respect and a child-centered approach to education are the driving force behind the school. The class size is small, the teachers know the children intimately, and the parents are an integral part of the community.

I am an advocate for Nora (as I am for all my children), and she is one for herself. Yet, in no way does stuttering define her. About a year ago, when she asked to join a local theater company, we obliged. She plays the piano, has many friends, and does what any seven-year-old would do. In addition, she stutters, but at the young age of seven has grown and become more self-confident than many children I know 5 times her age. I have such pride in this remarkable person. I hope to describe to you an incident that created great pain for both Nora and me, but as is often the case led to remarkable growth and learning.

One late winter day I picked up Nora from school and almost before we were out of the parking lot she reported being teased during PE over her stutter on the word, "snow". Nora was very verbal and sad about the teasing. She described three boys teasing her in PE and then three girls who supported her and were not quiet "bystanders" to the conversation, but instead stood up and said this was unacceptable. Nora and I made a plan. Nora wanted to write a note to the boys telling them she was sad and disappointed that they teased her. She also wanted to plan a presentation to her class.

The two of us went to the NSA website. We chose materials she wanted to share with her class and ordered them. She e-mailed Tammy Flores (director of NSA) with specific questions. Over the coming weeks Nora and I both communicated with Tamm,y and she was very responsive to Nora's questions and her request for information. We ordered the information Nora wanted to share with her class and planned our "talk".

In the meantime Nora wrote a note to the boys who had teased her. I communicated with her teachers about the incident. Nora took her note to school and one of her teachers, Laura, asked if she would like support in presenting the boys with the note. Nora said yes. What I remember hearing about that hour together is the following: an intense determination on Nora's part not to just "accept"

this behavior; a commitment on Laura's part to take as much time as necessary for this conversation; and eventually a "coming around" of the three boys.

Laura then asked Nora if she wanted the three girls who had supported her to join the conversation. She did and they were invited into the room. The girls would not accept, "can't we just forget about it?", and "I said I was sorry" from the boys. Nora's friends were vested in assuring that the boys deeply grasp the impact of their teasing. I believe (and research supports) that in the case of teasing or bullying it is actually the active bystander who often makes the difference, changing the dynamic and preventing the continuation of the teasing/bullying.

Nora and I presented to her class. Although I did the presenting, Nora sat with me and we both fielded multiple questions from the students. Nora was clearly proud of the fact that she was able to share this with her friends/classmates. Fortunately there was new research about the role of genetics in stutterers that had just been released to the public; (New England Journal of Medicine, February 25, 2010; Genetic Susceptibility to Stuttering), it was good timing for us. In addition to providing information on the science of stuttering we were able to encourage active bystanders. By providing information and talking about how friends supported Nora we were also educating in hopes of preventing future episodes of teasing of any sort.

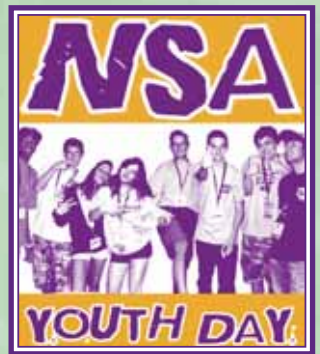
Over the following days, conversations moved Nora forward in her understanding and commitment to be an advocate for herself and to support others who might also be teased. I firmly believe that because of this incident, and the way in which it was handled, Nora has an even greater drive to ensure others are not teased and harassed about anything.

By following Nora's lead we were able to turn this situation into a positive experience and to educate others. We are open about stuttering in our family, it is never the pink elephant in the middle of the room. Her siblings know she can't stop stuttering, they patiently wait for sentences/thoughts to end. As she moves out into the larger world it is inevitable that people will step back, notice her stutter and wonder. I hope that by the time she is faced with the bigger world she will continue to advocate for herself and educate others about stuttering, something she did so beautifully in this situation. Nora has internalized stuttering as something she deals with on a daily basis, but by no means does she allow it to define her. I hope the same for every child that stutters.

BACK TO SCHOOL

Encourage students to talk about stuttering to their classmates. Some kids even do a classroom presentation about stuttering. The NSA has a guide to help them.

Children and teens who stutter sometimes experience bullying and teasing in school. The NSA has some advice and a Booklet. Find more Back to School advice at www.westutter.org.



Upcoming Continuing Education Seminars:

Greensboro, N.C.
October 16th

Phoenix, Arizona
October 23rd

Find a Speech Therapist!

Selecting a speech therapist is an important and highly individual decision. Speech-language pathologists with the Certificate of Clinical Competence (CCC) are considered qualified to treat a broad range of speech disorders, including stuttering. Because stuttering is a low-incidence disorder, however, many clinicians who hold ASHA's CCC may have limited training or experience in working with people who stutter.

There is no "best" method of speech therapy for stuttering. While most treatment approaches work for some people who stutter, no single method works for everyone, regardless of the advertising claims for some therapies. Research shows that people who stutter see the most successful treatment outcomes when:

- The clinician is experienced in working with people who stutter; and
- The clinician and client have a "therapeutic alliance" that enables them to work well together.

So it's essential that you speak with potential clinicians and ask about their experience and comfort level with people who stutter, their treatment approaches, and their expected outcomes after therapy. Often, the specific questions you ask are not as important as your level of confidence that the clinician is the right one for you. Many speech language pathologists will offer a consultation prior to initiating therapy in which you can ask questions and gauge your own comfort level in working with this professional.

Here are some resources to help you identify clinicians who focus on stuttering:

- The Specialty Board on Fluency Disorders has a list of speech-language pathologists who have advanced training

in stuttering and meet peer-reviewed standards as board recognized specialists at www.stutteringspecialists.org. Specialists are generally familiar with their colleagues. If you cannot find a specialist near you, or they are not accepting new clients, it is appropriate to ask a specialist for a personal referral. This may be someone they know, perhaps not a Board Recognized Specialist, but someone with expertise and interest in treating stuttering.

- The Stuttering Foundation of America has a referral list of speech-language pathologists who have a special interest in stuttering at www.stutteringhelp.org.

- The NSA also can help you find a speech-language pathologist in your area who is active in the NSA or has participated in our continuing education program. Contact the NSA office at (800) We Stutter. The NSA does not warrant the competency of these speech pathologists nor guarantee their treatment. As with any referral, speak with the professional and ask questions.

- Find a meeting near you by using the following link: <http://www.westutter.org/connect/localSupportGroup.html> and ask around. Sometimes group members and chapter leaders are familiar with local speech pathologists with an interest in stuttering. Participating in a support group also can help you get the most out of speech therapy. A survey by the NSA showed that support group participants are more likely to have successful speech therapy. The website is www.westutter.org/stutteringInformation/NSA_Survey_Results.html

The Specialty Board offers some tips on how to choose a speech-language pathologist and what questions to ask: <http://www.stutteringspecialists.org/SBFDGuideForParents.pdf>



FAMILY VOICES is a forum for views and information about stuttering directed toward families of the NSA. The opinions expressed are those of the individual contributor, and are not necessarily the opinion of the National Stuttering Association. The NSA accepts no responsibility for the accuracy of any opinion or information provided by the contributor, nor do we endorse or reject any therapeutic strategies, programs or devices mentioned in these pages. FAMILY VOICES is published by National Stuttering Association through the collaborated efforts of Bonnie Weiss, Gary Rentschler, Marybeth Allen, Debbie Nicolai and Sarah D'Agostino, as well as the many NSA members who wrote letters and articles for inclusion.