

Family Voices

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

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From One Parent to Another...

Debbie Nicolai, Family Programs
 Co-Chair



Hello Friends,

Summer is over and it's Back To School time! I hope that you have used the NSA website for the free informational brochure downloads for your teachers. They are a great way to educate teachers about stuttering and how to help your child in the classroom.

What about those IEP meetings? I used to hate those beginning of the year meetings, "Your daughter still stutters so we will continue her speech therapy." I prayed every year that they would tell me something new but alas it was always the same. I learned after a few of these meetings that I could say what I felt and what I wanted for my daughter and they listened! I was there as a member of the IEP team but I never realized it. I forgot that I was there as an advocate for my daughter and not the "Victim Mom." I wish I had spoken up sooner and had known that I was an important part of the team. No one knew Stephanie like I did and no one loved her like I did. Why did I think that they could plan her treatment with no

input from me? I learned late but I learned that what I had to say was important.

As you go into your annual IEP meeting, feel confident that what you have to say matters. The rest of the team will listen to you and respect you for your input. You have rights as a parent of a child receiving special services. Read the Parents Rights fact sheet and know what your rights are before going into your meeting. Ask questions about anything that is not clear to you or about a term that you do not understand. Offer information about your child that the others may not know, i.e., level of stuttering at home, ongoing private therapy, secondary behaviors, etc., anything that you feel could affect your child's therapy should be shared.

You know your child better than anyone, be a part of the team and help to make your child's speech therapy the best that it can be for him this year.

Good Luck! Please contact me with any questions or comments. Let me know how your IEP meeting goes! You are Not Alone!

One Parent to Another... 1

Marybeth's Message 1

Ask the Expert 2

Teen Advisory Council Member Tells his Story 3

Parent's Perspective 4

Stutter Buddies 5-6

Ask Me- by an NSA Teen 7

Sarah Says... 8

NSA-Kids & TWST Groups... 8

Marybeth's Message: "Back to School"

Marybeth Allen, CCC-SLP-
 Family Programs Co-Chair



I have an empty nest now, but I have mostly fond memories of late August and getting the kids ready for school. One memory, though, is not so fond – my memories of worrying about how my son's stuttering will affect him in this upcoming new school year. What will the

new teacher be like? Will there be new kids in his grade...will one of them be a potential bully? If you are a parent of a child or teen who stutters, you know what I'm talking about! You've been there; you are there.

This memory was refreshed for me this summer at the NSA conference in a workshop I led called, "What Bugs You". In the "fun" part of the workshop, the kids crafted a "bug" from a Styrofoam take-out box. The serious part came when the kids shared what bugged them, wrote it down on paper, and put it in their Bug Box. It turned out that one of the common themes of the kid's complaints was ... "My friends tease me when I stutter". Hmmmm...I wasn't surprised.
continued on page 2...

Graduating to the Big Leagues by Alex Rosenbaum



I first discovered the NSA through my speech therapist Dale Williams nine years ago. Learning about the NSA was such a relief for my family and me. We all were so excited to learn about a place like the NSA where people who stuttered could just be themselves. My most vivid memory at an NSA conference would have to be at my first conference which was in Chicago in the summer of 2000. When my Dad and

I first walked into the hotel, neither of us had any idea what to expect. As soon as we started to meet people such as Tim and CJ Bryant and Nina Reeves, we knew this was a place where I could let go of my stuttering fears and just be myself. Something that really made me feel comfortable with my speech was learning that I wasn't the only one that stuttered and that there were people just like me.

Going to the support group in my area which is in Boca Raton, Florida and lead by my SLP, Dale Williams has been great. We have a meeting every month and we usually get an average of five people. At times I am the only teen/young adult that attends the meeting. During our meetings we talk about many things: how our speech has been the past month, what we can do better in the next month to help our speech, and many other topics. In the future I do hope that I can lead an NSA Chapter.

It took me a few years after joining the NSA to finally accept my stuttering. Before I became accepting of my stuttering I used to have a lot of avoidance behaviors, such as changing words and using um's and ah's and at times I thought I was the only person who struggled with stuttering. There have been a lot of people who have helped me learn to accept my speech. To all of them, thank you very much for helping me along the path to accepting my stuttering.

My parents have learned a lot from the NSA and they continue to be involved to help other parents. When we first joined the NSA I think their biggest goal was be

able to learn how they could help me in my journey to accept my stuttering. Another thing they wanted to learn was about stuttering in general. Until finding the NSA we really didn't know much about stuttering at all. I never knew that there were so many famous people who stuttered; I never knew that there were intensive programs like SSMP and many other things like that. In recent years my parents have been learning how they can help other parents with children who stutter.

Being on the NSA's Teen Advisory Council has been an amazing experience. Being able to work with all of the teens and our mentors, Debbie Nicolai, Marybeth Allen, and Nina Reeves, has been wonderful as well and I would like to thank them all. Being able to work on the NSA's Board of Directors has been a great experience as well. I have learned so much from all of the past and present board members and I look forward to one day being able to work with them more in the future. I think the Board meetings are a great experience. Being the only teen/young adult on the board was interesting. There were times when I had no idea what they were talking about, but I did learn a lot! I think the NSA Board members listened to everything that I had to say and I think that they truly did respect my opinion.

I believe that the future of the NSA is a bright one. I hope that the NSA will continue to change the lives of people who stutter and provide support for those who stutter and their families. I also believe that the future of the NSA Teens is bright too. I remember when we joined 9 years ago the conference weren't all that big. I truly believe that the NSA will be huge in the years to come. We keep growing in attendance every year. I know that through the next years the teens will continue to grow larger and will continue to be the future of the NSA. As an adult I look forward to being involved in the NSA in any way that I am needed. I am a little nervous about become a member of the Adults at NSA. I have been with Family Programs for so long and have become attached. I am glad to experience something new and see what I can do as an adult. I hope to one-day present workshops as an adult and to even maybe be on the board again! I would love to continue to give back to the NSA as much as it has given me for the past nine years. By knowing the people in NSA I have made so many new friends for life.

Throughout the year I keep in touch with many of my NSA friends through Facebook, IM and even the phone! Being able to communicate with them makes the year between conferences go by so much faster. I want to thank all of my NSA friends for being the great people that they are.



NSA Teens ... 2008 Conference

Parent's Perspective

By Joan Ross

When my daughter Courtney, came to me in the summer of 2007 and asked me to find her somewhere, anywhere that she can go and meet other teens who stutter...I was just so excited. Finally I thought!! Finally my daughter, who had started to stutter when she was first old enough to talk, might be ready to share her stuttering with others!

So naturally I did what any other parent now days would do next. I immediately jumped on the internet and Googled : The National Stuttering Association. After exhausting every link on the NSA web page however, I did not find a teen group in our area (which I am in the process of changing) but what I did find instead was that the next Annual NSA Convention was being held in our very own state of New Jersey. Parsippany was only one hour away from our home town. What luck...I felt like it was meant to be.

Ten months of planning and waiting and the day was finally here. When we arrived at the hotel, my husband David, my oldest daughter Heather who is 22, Courtney now 15 and me... we really did not know what to expect. We were excited, anxious and very nervous. I just kept reminding myself why we were here and that was for Courtney. My daughter needed to see that there were other people who stuttered just like her, beautiful, smart, successful people who stutter. I also remember saying to myself "if in a few days we leave here with Courtney making one new friend, just one" ... it will all be worth it.

Well, what I really didn't expect was what happened next. Once inside we were greeted with such warmth, such friendliness and so much kindness.... We were immediately embraced and made to feel completely at home. It was overwhelming....and it wasn't long before we were expressing ourselves in the same way.

Within hours, members of the Teen Advisory Council (TAC) had already taken both my daughters under their wing while my husband was busy making friends, shopping the NSA Store and for days bidding on all the items in the "Silent Auction"(we won't talk about the underwear that don't fit!).

And as for me, I was busy planning our weekend and all our workshops. You see... being a mother of a child who stutters, I thought I knew all there was to know about stuttering. But I was so wrong. All the workshops that we attended were so informative, so heartfelt and so much more enjoyable than I could have ever imagined.

I can't begin to tell you how much more I learned, how much guilt I was able to unload and how much closer to my daughter I was able to become.

Courtney however, being this was her first convention, picked and chose her workshops carefully, promising to

become more involved next year. But we were all so proud of her....this whole convention weekend was a huge step for Courtney. My daughter would rather go through life not speaking at all before she'd anyone know she stuttered.

I don't really know if Courtney ever really let her guard down fully in the whole time that we were there. But what I do know is that whether it was The Opening Ceremonies, or the crazy hotel fire drill or the magnificent trip into New York City or the fun filled Saturday Night Banquet where everyone danced until the wee hours of the morning, my daughter had amazing fun. She made friends and memories that will last her a lifetime. And she did it all in just four wonderful days.

I remember at registration when we learned that the theme for the conference was The Wizard of Oz we just couldn't believe it. It was very emotional to all of us as a family because The Wizard of Oz was Courtney's all time favorite movies when

she was small. She would watch it over and over again. She would actually cry from freight every time the Lion would jump out of the woods when first meeting Dorothy. This is why I thought it was just so ironic when on the day of Closing Ceremonies (which was actually the high light of the convention for me) that I was asked to be the Lion in search of Courage, the very same thing that brought us to the NSA to begin with...our search for courage. Courage to help my daughter learn to accept that stuttering is a part of who she is. A beautiful,



The Ross Family

amazing part of who she is.

When I was asked to be the Lion, All I could think of was how?? Being on such a heightened emotional roller coaster since arriving at the convention, I wasn't sure how I was even going to speak. I spent over an hour crying while I put this whole speech together on paper. But when it was finally my turn to go up on the stage, I didn't even need that piece of paper to find the words to describe my daughters search for courage.

Still crying however, it was at that moment that I also knew that my family would leave there not only with that courage but with more knowledge, confidence, and friends and with more family than we came with....and that felt so good!

I can't express to you how much, in such a short period of time, The National Stuttering Association has changed our lives. It has been nothing short of a miracle, one that we've been waiting a very long time for.

Post NSA 2008 Conference..... After arriving home it took us weeks to just unpack and unwind. Not a day went by where we were not laughing or crying, looking at pictures or cell phone video's or just talking about the unbelievable time we had.

We miss everyone and we thank everyone from the bottom of our hearts for letting us in and allowing us to become a part of this amazing family.

Arizona here we come.....

Stutter Buddies

Experience with Stuttering ... By Katie R.

Dear Stutter Buddies,

My name is Katie R. and I am from Central Pennsylvania. Let me tell you about my experience with stuttering. I just started at a new school. That means new classmates, new friends, new teacher and most of all A NEW SPEECH TEACHER. I had a hard time making friends, and I thought it had to do with my stuttering. When I did make a friend I asked her, "Did you know I stutter?" Her reply was "NO!" I couldn't believe it. It was the greatest feeling in the world! She didn't even know I stuttered! AWESOME!

Your Friend,

Katie R.



What I learned at the NSA conference!... By Julia



Dear Stutter Buddies,

This year at the NSA Convention, I learned that stuttering is okay and it's nothing to worry about.

From Julia

Find the
NSA Kids/TWST
chapter locations

- Dallas
- Chicago
- Lafayette
- Rochester
- Longview
- Sacramento
- Charleston
- Orlando
- Detroit
- Boston Area

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Stutter Buddies

Siblings!! By Kayla W.

Dear Stutter Buddies,

I came to the NSA Conference this year with my brother Danny. It was really fun. I got to go to New York City and see Ellis Island and the Statue of Liberty. We also met Cam. Ever since Cam and the rest of us got dismissed early from a class and almost got lost, we've hung out more. We've exchanged addresses and my siblings and I hope we keep in touch. I also met Allison. Allison is 13 like me and she stutters. I feel that it's important to listen to my new friends and give them time to say what they need to say. They're just like me except for stuttering. I don't see stuttering as a barrier between us. It's just a unique quality of our friendship.

From Kayla W.



Open Mic! ... By David

Dear Stutter Buddies,

Today I went to the stuttering convention. It was fun. I met a lot of new friends like Ben, David and Sean. My favorite part was the Open Mic because if I stuttered, no one would make fun of you. It was very hard to talk to my friends because they made fun of me.

Bye,

David



Stutter Buddies Stories and drawings may be submitted for publication.

Send them to the NSA or to Bonnie Weiss at 1484 Kensington Avenue, Buffalo, NY 14215 blweiss1@verizon.net

Ask Me

By: Sarah Onofri



"H-h-h-h-h-i m-m-m-y name is S-s-s-s-arah" "What, did you forget your name?" When I introduce myself I sometimes get this response. I

am a person who stutters. Each and every time this happens, I am baffled that people can be so ignorant and rude. As soon as I clarify that no, I didn't forget my name, I stutter, my interlocutor begins to apologize profusely. I thought I would take this opportunity to save people this embarrassment and make an attempt to educate others about stuttering.

I wasn't always so open about my stuttering, but that all changed a few years ago when I gave a speech about stuttering to my English class. I stood in front of my peers, stuttering through my presentation as they sat listening attentively. For the first time I knew that they respected me and were listening to me to hear what I had to say, rather than noticing how I said it. My peers were genuinely interested in stuttering and wanted to learn more. The idea that I was able to make thirty more people aware of stuttering and how it affects people made me feel proud. It also made me feel more comfortable and created a safe space for me to speak in that class.

One percent of people in the world stutter and some of these people include James Earl Jones, Carly Simon, and Lewis Carroll. Stuttering is more common in young children, but as it has in my case, stuttering some-

times stays with people through adulthood. Why do people stutter, and what causes it? Although there has been a great deal of research done on stuttering, there are still no definitive answers to these questions. Researchers do know, however, that stuttering is a developmental disorder of the brain and is sometimes found to be genetic. The cause of my impediment is a mystery, but it is something that I must always struggle to overcome.

The biggest misconception about stuttering is probably that people stutter because they're nervous. This is not true. There are certain situations that may cause people with this impediment to be more dysfluent than usual, but stutters don't stutter simply because they are nervous. I don't feel particularly nervous asking my mom to pass the salt, but it can sometimes take me a full minute to make the request. And speaking in front of a large crowd fills me with apprehension, but I have spoken fluently before an audience. Also, the condition does not affect every speaker in the same way. More severe, intense stutters are more "tense" because there is more tension in their neck and throat while speaking. The tensest kinds of stuttering are called blocks. On the other hand, word and sound repetitions are a less tense form of stuttering.

There are a lot of treatments out there for stuttering. One of the ones I've participated in is speech therapy. Speech therapy teaches techniques for getting unstuck from the moment of stuttering. Therapy also focuses on learning to accept stuttering as a part of oneself. For me, therapy helped to shape my ideas about stuttering and myself. I had been ashamed of my stuttering, feeling like I had to hide it, but I came out of speech therapy realizing that stuttering is just another part of me. I learned that stuttering is perfectly alright.

The National Stuttering Association was also a big part of my journey to acceptance. They not only offer support for people who stutter but also for listen-

ers. Here are some tips: "Be patient." This means don't interrupt me to "help me" finish a sentence. This intervention makes me feel annoyed. "Be patient" also means don't start glancing around the room as if you're in dire need of an escape from my next sentence.

"Remember that stuttering is not caused by nervousness." This means you don't have to pat my arm and say "Honey, its okay." You may be nervous, but I'm not.

And finally, "If you're not sure how to respond, ask me."

- Check out an interview with Sarah on ww.StutterTalk.com! Many wonderful interviews can be found there of kids & teens at the NSA conference.

SEND YOUR STORY! SEND PHOTOS! SEND US QUESTIONS!! SEND THE NSA IDEAS!

Family Voices would like to hear from YOU! Please send us your thoughts, ideas, questions and stories YOU can help the NSA... with the annual conference, offer guidance and support, participate as mentors in NSA Youth Days, or write your own article for Family Voices!

Contact the NSA or Sarah D'Agostino at sdowgiallo@yahoo.com



Teachers are People too?!

Sarah D'Agostino
Family Programs
Administrator

The first day of school... those words evoke a feeling similar to waiting in line for a giant roller coaster. Excited and scared— should you sit in the front, in the middle or the back?! Some of my most vivid childhood memories are from the first day of school. It was the chance to make an all around first impression. Sometimes it turned out alright and other times not so good. In the fifth grade, my family moved and I went to a new school. The teacher didn't know I stuttered and asked me my name. When I couldn't get it out, he said, "What you don't know your own name?" I laid my head in my arms on my desk and started to cry. We soon worked it all out and by recess I had new friends and was loving life.

These days, I have a lot of friends and family who are teachers. Surprisingly, teachers are real people too and they too are anxious for the first day of school. They want to make a good impression. They really want the students to like them but they also have to set the tone for their classroom. Knowing this means that there is tension in the room from all sides. The greatest way to alleviate some of the tension is to disclose the fact that you stutter by either talking to the teacher ahead of time or writing him/her a note.

The NSA's family programs and all of its members are here to help. We have grown this year by adding resources to the website and support groups around the country. We look forward to hearing how your first day of school goes!

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.

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**National
Stuttering
Association**

Changing the lives of people who stutter

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**NSA-Kids and TWST chapters across the US!...
Check the www.WeStutter.org for
contact information!**

The "award winning" **Dallas TWST chapter** leaders met over the summer to layout the plan for the school year's meetings... Big plans...

- **August:** Back to School issues: Dealing with new listeners and teachers
- **September:** U tube Video night: In preparation for the October "awareness" national campaign
- **October:** Fun night...social event (bowling or something!)
- **November/December:** Holiday Party and stuttering as a gift
- **January:** NY Resolutions (national)
- **February:** Stuttering brains with Stuttering Jeopardy and teach parents to stutter (national)

Leader contacts: Nina Reardon Reeves at nina@mtco.com and Brian Wages brianwages@yahoo.com

NSA Kids/TWST group in Roseville-Sacramento, California lead by Nancy Barcal recruited a wonderful group of volunteers to share information about stuttering with the community at the two day, *Access to Care Expo* held on August 22 and 23, 2008 in Granite Bay California. The fair opened with a wheelchair basketball game with area sports star Ruthie Bolden-Holifield of the Sacramento Monarchs. The NSA office donated fliers and booklets as well and NSA chapter banner!

Leader contact: Nancy Barcal at nbarcal@surewest.net

ACTIVE GROUPS...

- Dallas, TX
- Longview, Texas
- Sacramento/Roseville, CA
- Charleston, SC (NEW!)
- Orlando, FL (NEW!)
- Rochester, NY
- Chicago/Naperville, IL
- Lafayette, LA
- Brooklyn College, NY

UP & COMING GROUPS...

- Mesquite, TX
- S. NH/Boston, MA
- Detroit Area, MI
- San Diego Area, CA
- New Jersey

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