

# Family Voices

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

119 W. 40th Street,  
 14th Floor, New York,  
 NY 10018

800.WeStutter  
 (937.8888)  
 212.944.4050

info@WeStutter.org  
 www.WeStutter.org

## From One Parent to Another...

Debbie Nicolai, Family Programs  
 Co-Chair



*The holidays are here again and that means changes in bed times, eating habits, and guests at your home and visiting homes of friends and family.*

I love this time of year but always dreaded it because the stress of the holidays and all of the changes from our usual schedule meant that Steph's speech would reflect these changes. Her usual mild stutter would become moderate with longer blocks and fewer times of fluency. Stress, sickness and schedule changes affect her speech, I have no doubt about that.

I have been asked by many parents about this exact thing, "Why does my child stutter more during school breaks or while he is working on a school project or during times of stress and what can I do about it?" I asked Scott Yaruss, PhD for help with this and a shortened version of his response, "Increased emotional tension leads to increased physical tension and increased physical tension makes it harder to plan and execute speech motor

movements. In general, any time somebody isn't feeling at their best (nervous, fatigued, upset, etc.) it affects their fluency...just like clumsy people get more clumsy, people who bite their nails become more likely to bite their nails, etc... well, people who stutter become more likely to stutter."

"As for what to do about it -- YES, face the fear. If what you fear is stuttering, then trying to avoid stuttering won't actually help in the medium or long term (though there is a short-term release from the fear in that situation). Ultimately, though, the fear grows unless you face it. So, at the beginning of these transitions, increasing the active use of fear-reduction strategies can help this period become shorter."

So there you have it. It is all normal behavior for our kids and for us. Stress and changes do affect each of us in different ways. So go hug your kids and tell them that the holidays, as wonderful as they are, can cause stress but it's OK. Everything will be back to normal soon enough. Happy Holidays! ●

One Parent to Another... 1

Marybeth's Message 1

Ask the Expert 2

Hitting It Head On 3

Teens Talk to the Media 3

Parent's Perspective 4

Stutter Buddies 5-6

Yahoo Groups 7

The Workshop 7

Sarah Says... 8

NSA-Kids & TWST Groups... 8

## Marybeth's Message: "Making Therapy Decisions"

Marybeth Allen, CCC-SLP-  
 BRF-FD

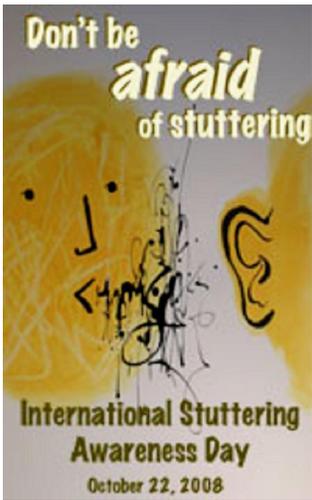


A parent's natural inclination is to "seek out the best for my child", and this is certainly true in regards to finding help for your child who stutters. There have been recent questions on our NSA Parents Yahoo Group about therapy (e.g. private versus school-based). Other questions often heard are: "What's right

for my child". "How about therapy X that I've heard about from my doctor (or neighbor or mother)?" "Would my child make more progress if he focused on fluency rather than easier stuttering?" I saw the ZZZ device on TV. Do you think my child would benefit from it?" Putting on my SLP hat, I thought this might be a good time to address a related issue in this Family Voices column - "How can a parent help their child's speech-language pathologist (SLP) make decisions towards the best therapy approach for their child?"

First, parents need to know that your child's SLP shares your goal, but when

Marybeth's Message cont on page 4...



International Stuttering Awareness Day  
October 22, 2008

NSA members and people who care about stuttering take day to be especially conscious to educate themselves and others around. There are all sorts of things you can do to be an active part and a valuable participant. More information and links to the online conference can be viewed on the NSA website.

[www.WeStutter.org](http://www.WeStutter.org)

ADVERTISING  
WRITING THE MEDIA  
ALONE NO MORE  
REPLENISHING THE SPIRIT  
EMPATHIZING  
NEW IDEAS  
EMPOWERING  
SHARING ONE VOICE  
SPEAKING FREELY  
DISTRIBUTING HELPFUL INFORMATION  
ACKNOWLEDGING OUR HISTORY  
YOU CAN MAKE A DIFFERENCE

Stuttering Awareness Week is the second week in March. Think about what you might like to do to be more increase stuttering awareness!!

**Dear Ask the Expert:**

**What other factors besides heredity could be the reasons that people stutter?**

This is a great question! This is also an important question, because until we fully understand what causes stuttering, we can only treat the *symptoms* of stuttering. As the question implies, there is an undeniable genetic component to stuttering. If you do stutter, you're about three times more likely to have a relative who stutters (Andrews, 1983). We also know that stuttering is not *entirely* genetic. Several people have been identified in the world who stutter, but have an identical twin who does not; if stuttering were entirely genetic, this would be impossible.

Causation can be broken down into 3 categories:

*Predisposing* factors – What makes people *susceptible* to stuttering?

*Precipitating* factors – What makes people *begin* to stutter?

*Maintaining* factors – What makes people *continue* to stutter?

For this article, I want to talk primarily about predisposing factors.

Research is teaching us more and more about stuttering. Brain scans are beginning to shed some light on how the brains of people who stutter (PWS) differ from brains of people who don't stutter; for example, while speech and language are processed almost exclusively in the left hemisphere for the vast majority of the population (somewhere around 95%), studies are showing that brains of PWS are far more likely to have speech and language processed in the *right* hemisphere, or distributed more evenly between the 2 hemispheres. Alas, this is not the case for all stuttering brains; and, we can't say whether the unusual wiring in some brains causes stuttering, *or* if stuttering leads to atypical brain wiring.

If we abandon physiology for the moment, I have a behavioral model which I use sometimes to help students and parents better understand how stuttering may come about (and why it stays with some people and not others). Imagine that everyone is born with a certain measurable predisposition (a 'dosage' of sorts) for stuttering; if it runs in your family, you are likely to be born with a larger 'dose' than most. Now imagine that this dosage is like a stick, stuck in the bottom of a pond. If the stick is long enough, *or* of the water is shallow enough, we can see the stick. The length of the stick will never change, but the water level in the pond certainly can. Now imagine that the water level represents the 'threshold' for stuttering, and when the stick is visible, stuttering is present. The stick (stuttering) may be barely perceptible, or it may be hard to miss. The water level (threshold) can rise or fall,

due to any number of factors; physiological, psychological, or environmental.

Several observations make this dosage/threshold model for stuttering development compelling:

- Speech is both a language and a motor task. As language and motor skills are rapidly developing in young children, the threshold will be lowered, and indeed many young children begin to stutter. We know that girls mature more quickly, and indeed more girls 'grow out' of stuttering than boys. If girls do have a higher 'threshold', this may help explain why they are less likely to have all speech and language disorders than boys.
- For many PWS, stuttering goes up as fatigue sets in. If the threshold is variable, then surely fatigue would compromise it. Stuttering can vary not only throughout the day, but also from week to week, or month to month. Physiological changes could impinge on the threshold; many PWS stutter more when they are in poorer health.
- If there is such a threshold, it could also be tied to fear and anxiety, which we know correlate highly with increases in stuttering. It is also worth noting that emotions are predominantly processed in the right hemisphere.
- Girls who stutter have more stuttering relatives than boys who stutter (Andrews & Harris, 1964). Likewise, girls who stutter should on average have a higher predisposition ('dose') of stuttering than boys who stutter. This would be consistent with the belief that girls have a higher threshold than boys (see #1).

Remember that I have not addressed *precipitating* factors, which trigger the *onset* of stuttering, or *maintaining* factors, which allow stuttering to continue and progress. All three types of factors work together to result in chronic developmental stuttering. ●

Charley Adams,  
PhD, CCC-SLP  
Clinical Assistant  
Professor  
Dept. of Communication Sciences & Disorders  
University of South Carolina



Mid-Atlantic  
Regional Chapter  
Coordinator  
National Stuttering Association

**HITTING IT “HEAD ON”**

**Ben North**  
14 years old, Shrewsbury, MA

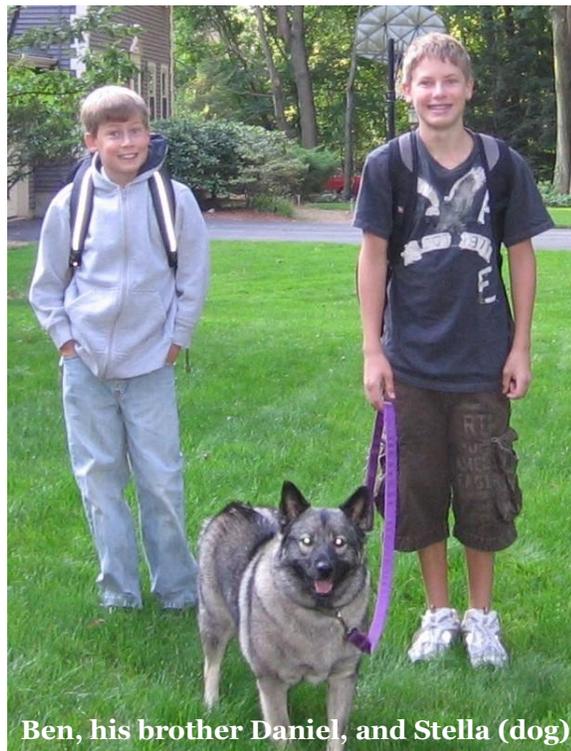
seemed like no big deal to me, because in elementary school kids just ally try and find little things, like your in front of your class or team, the kids will constantly make fun of you. That’s a problem! Not only that, some kids won’t make fun of you, but if you don’t talk about it (stuttering) they will feel uncomfortable because they don’t know if you know that you talk like that. So, they are scared to say anything.

About 1/2 way through the year, a few kids just really started making fun of me. I got annoyed and I said “you know what, I’m just going to give a presentation to end this”. My team (100 kids in all) met on every Day 5 (in a 6 day cycle). My teachers said at the first team meeting that kids can present anything they wanted. For example, one kid actually brought in his Xbox 360 and played Halo with the rest of the team. So, I asked my LA teacher if I could present my stuttering. She said yes and that she has a friend who stutters. I was really nervous, but in the end, I did it! I talked about the major points, how people don’t know what causes stuttering, how people don’t stutter when they sing, how there are many types of stuttering, and how it has nothing to do with a person’s intelligence. I also discussed what annoys me about what people say about, and how they react to, my stuttering. I was actually grateful for the amount of questions that people had because you don’t want them to have the wrong idea about stuttering. I remember a few questions that the kids asked me:

1. Is it contagious?
2. Do you know that you’re stuttering when you are?
3. Are there certain sounds that are harder to say?

After the presentation I noticed that people were respectful to me and people stopped making fun of my speech. Some actually defended me when others made fun of me. So, all in all, it was a good idea to give a presentation. And, I’m only in my second month of 8<sup>th</sup> grade and just finished my second presentation to my class last week! If you are thinking about talking about your stuttering to a big group, go for it! If you want to, but you’re too nervous and worried that you’ll stutter, you shouldn’t be nervous because that’s what you’re talking about. So, you actually want to stutter as a way of giving examples. Thinking of it like this may help to take the pressure off.

I’ve stuttered since I was five, and now I’m in eighth grade. But the real story happened when I was in seventh grade. I got an award for giving a stuttering presentation to my team of 100 kids. It but apparently it was. Well, middle school is different from elementary school accept you for who you are. But, in middle school kids they don’t; they actu-speech, that are weaknesses. So, naturally, if you don’t talk about it (stuttering)



**Ben, his brother Daniel, and Stella (dog)**

**Teens talk to the media:**



By Sarah D’Agostino

In honor of International Stuttering Awareness Day, October 22, many newspapers across the country chose to do a story to help raise stuttering awareness. A few of our very own teen NSA members were the topic of such articles. They were brave enough to share stuttering in a personal and honest way so that the public can be better informed.

Elliott, a 14 year old from California gave advice to listeners. He said, “Listen to what we’re saying, hold off on the advice to relax or take a deep breath and, oh please, don’t finish our sentences...I do stutter, but please don’t try to fix me.” said Elliot.

Another article talked about Chloe, 14 year old NSA and TAC member from California. Chloe and her mom told reporters about the NSA’s support groups, workshops and conferences. The article said, “Discovering other kids like her was ‘the best day of her life,’ her mother says. Now Chloe gives back by assisting in those workshops, helping other kids who stutter and letting them know that they are not alone.

To read the entire article about Elliott and Chloe see the NSA website (what’s new? section) or contact the NSA. ●

**Parent’s Perspective**

By Cindy Hunt from Rhode Island



Last April, I was informed via a letter from the School Department that my son was no longer going to be receiving speech services for stuttering through an IEP. New legisla-

tion in Rhode Island terminates all stand alone speech services after the child reaches age nine. My son was turning nine in June. I was appalled that my son’s age was the sole determining factor for speech therapy. He had been stuttering for four years and he obviously still needed therapy, turning nine would not change that fact.

I was determined to stand up for him; he needed me to be his voice, now more than ever. With the support of my son’s private speech therapist I began by writing letters to our health insurance provider as well as the Department of Education in Rhode Island. I also contacted our local legislators and the Director of Special Education in our town. The last thing I did was to make a call to my son’s school principal. As it turns out, the principal was our biggest supporter. Once she knew our situation, she acted immediately. She observed one of his therapy sessions with the school therapist and agreed he needed to maintain speech therapy. She willingly wrote a 504 education plan with classroom accommodations and weekly speech therapy. The plan was in place for him once the IEP became void.

*“I was determined to stand up for him; he needed me to be his voice, now more than ever.”*

Feeling encouraged, I decided to continue with the momentum I had going by purchasing some materials for the classroom teachers from The Stuttering Foundation’s website. The school therapist facilitated the distribution of these materials and now every teacher who has contact with my son has access to the information. The team of educators involved with getting the 504 in place has been eager to understand my son’s needs and to help him in any way they can. Thankfully my experience was a positive one. I realize there are many families who aren’t as lucky. My advice it to stay determined. Advocating for my son was an enlightening experience; an experience I found incredibly rewarding. ●

**Family Voices would like to hear from YOU!**  
Please send us your thoughts, ideas, questions and stories

**Contact the NSA or Sarah D’Agostino at [sdowgiallo@yahoo.com](mailto:sdowgiallo@yahoo.com)**



**Marybeth’s Message cont from page 1...**

parents ask us these questions, the answers are rarely simple. Stuttering is just too complex, non-linear and multidimensional. Our profession also strongly recommends that SLPs be guided by evidenced-based practice (EBP) which means SLPs should make therapy decisions that are

- 1) research based,
- 2) client centered and
- 3) outcome focused.

It seems like a “no-brainer” that you would want your child to have a therapy program that has “high quality research based evidence of its effectiveness”. The bad news is that according to the 2005 ASHA Leader, “our field has a paucity of well controlled studies”. On the other hand , the good news is that, “The existing research base supports the conclusion that treatment programs exist that can effectively treat stuttering.” However with a note of caution, the Leader goes on to say that “much more research is required” in order to fully understand what factors makes a program effective and which programs are best suited for a particular child. By the nature of “group studies”, there will also always be children and teens who don’t fit the profiles of the population of subjects in the research studies.

So parents, please understand that it’s not just all about the best researched program! It’s important to look at EBP is a as a dynamic interaction between research based programs and the other two components of EBP: the client centered focus and the desired outcome focus. This is also where you, as parents, can have valuable input when your child’s SLP makes decisions about therapy approaches. You know your child the best and can be a valuable resource to the SLP. For example, if you know that your child has practiced and mastered “fluency tools”, but you also observe him/her using avoidance tactics to remove him/herself from talking situations or not using the phone at home, your SLP needs to know this. She/he then might add components of desensitization (e.g. voluntary stuttering, reading about famous people who stutter) to your child’s therapy goals. Or if your child is a teenager who has been in therapy many years and seems to “manage his speech fairly well”, you may help initiate a discussion about his/her outcome goals, which may at that point be “being an effective communicator” rather than 100% fluency. After reading this, I hope all of you better understand so you may be empowered to engage in the process! ●

# Stutter Buddies

## Fluency Strategies I Use... By Zach K.

Dear Stutter Buddies,

My name is Zachary. My nickname is Zach. I am ten years old and I go to Gateway Elementary School. I have lots of friends—too many to name. I have six rabbits and one dog. My dog's name is Buddie. I like playing sports. I play football, soccer and baseball.

I have been in speech for six years, ever since Kindergarten.

My speech teacher's name is Mrs. Sitek.

Most of the fluency strategies I use are pullouts and pausing.

Thank you for publishing this.

Your Friend,

Zach K.



## I Am Learning and I Am Not Alone By Curtis L.



My name is Curtis L. and I am eleven years old and I live in Niagara Falls, Canada. I am in sixth grade and I stutter. I have been stuttering since I was three years old. Its hard sometimes because kids tease me at school and it hurts my feelings but I know that they have other people out there that

support me including my family.

My mom has just recently tried to find a youth group that I can join with other kids that stutter. The closest one to us is the Buffalo Chapter of the NSA. Even though I am Canadian and they are adults they still welcomed me even though I am just a kid. I liked the way they welcomed me to the support group, not to mention Bonnie's brownies are fabulous!!!

Stuttering is a hard thing to go through and I know there is not a cure but I am learning that I am not alone and that there are people to help you through your hard times and good times.

When I grow up I would like to be a Speech Therapist to help other kids who stutter just like me.

Your friend,

Curtis L.



## Some Family Voices' Authors-

Alex Alina Allan Charley  
Cindy Curtis Devondre Gordon  
Sven Tucker Zach

r n n n o a h d e  
e d c a l s l n n  
g n h l i l v a l  
d o a t u c k e r  
k n r l r t l z n  
h u l d i c t y x  
c d e v o n d r e  
a l y u s n a a l  
z l z i i o c a a  
o a v c h l r o s

# Stutter Buddies

## Remember That you are in Control By Tucker B.

Hello,

I am Tucker B., a third grader at Oak Grove Elementary School in Corbin, Kentucky. I love to play football and I love to learn about animals. When I grow up, I would like to become a veterinarian.

I also am a stutterer and I love to talk! I've not always enjoyed talking because of my stuttering. Sometimes I think stuttering is bad because sometimes I get made fun of and I get mad because I cannot get the word out. On field trips some kids make fun of me, but I ignore them! It really doesn't hurt my feelings. Well, only a little. I say "You have a problem and I'm not going to worry about it!" That usually keeps them quiet.

Sometimes I think stuttering is good because I get to have fun at speech. And I know I'm not alone. Many famous people stutter, like James Earl Jones (the voice of Darth Vader). I am a Star Wars Freak and if Darth Vader can stutter, then it's okay for me to sometimes stutter! When Mr. Walz, the University of Louisville's women's basketball coach came to my school to speak, he told everyone that he was a stutterer just like me.

Everyone stutters. Sometimes it's easier to talk because I have easy starts. That helps me a lot. Be sure to do what your Speech Teacher tells you to do and do it EVERY DAY... not just when you are in speech. It helps when your parents know what the Speech Teacher is teaching you so you can practice your tricks at home.

If you stutter, keep doing your tricks and always remember that you are in CONTROL!

Your friend,  
Tucker



Front Row: Tucker Barton;mom Bille Jo, Grandmother, Arlene;Grandfather, Dr. Bruce Barton; dad Todd Barton, Coach Jeff Walz and sister, Ashley.

## Stuttering Art

Devondre M. of Washington D.C. portrays himself as going head to head with his stuttering. He plays a video game against his stutter and it look like Devondre is winning. Wh at an great perspective and artist!

This artwork was sent to the NSA by Tracy Higgins, an SLP graduate student at George Washington University who worked with Devondre at the fluency disorders clinic at the Speech and Hearing Center.




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

**Teens who stutter connect ... on the NSA Yahoo email Group...**

Get connected with other teens who stutter! The NSA sponsors a Teen Yahoo Group which is a web based listserve for teen who stutter. This Yahoo group was created to give young adult stutters aged 13-20 the chance to connect to youth who are faced with a common difficulty.

The group allows teens to share their frustrations, experiences and triumphs with others similar to themselves. You can write to the list to share experiences or just "lurk" to get ideas for dealing with stuttering in the real world. There is also a parent and kid's yahoo group!

If you want more information about becoming connected with other teens through the listserve send an email to Sarah D'Agostino, Family Programs Administrator at [sdowgiallo@yahoo.com](mailto:sdowgiallo@yahoo.com).

**Alina shared with us...**

I have been stuttering all my life. This year though, I have improved greatly. I love the NSA Teens Yahoo Group. I talk to a bunch of the teens and they help me and encourage me through my hard times. For instance, I had a speech I had to do in one of my classes and I was really worried about it. I posted it on the NSA Teens Yahoo Group and in one day I got 6 emails of encouragement. It helped calm my nerves and get me through my presentation! Thanks to all the NSA teens who helped me through that!

-Alina D.  
15 years old from Pennsylvania



**The Workshop by Alex, Sven, Gordon, and Allan**

We're a group of high school stutters who attended workshop at the University of Maine in Orono. We painted rocks to symbolize our stuttering. We also watched *Transcending Stuttering*, an informative video about people who stuttered and how they eventually conquered their fears about stuttering. Then when we joined "the parents", Allan stood right up and told them all what he had learned about stuttering and what "working on it" had done for him. We all "cheered him on"!

Some of the things we have learned and are still learning are:

- Hard work eventually pays off.
- Make friends to pacify those who make fun of you.
- Don't believe that the world looks down on you because you stutter.



Don't think you're worse than other people because you stutter. The ones who make fun of you are actually worse than you because the best thing they have to do is make fun of someone who stutters. It's ok to be different from society. Be self-confident.

We find that being nervous often causes us to stutter more and it's hard to use your strategies at those times. You have to anticipate it and accept that it happens. You need to learn to not care about your stuttering.

Just relax and be amazing!

Alex (age 16, Not pictured), Sven (age 16), Gordon (age 18), and Allan (age 15)

