November 2009 - January 2010

National Stuttering Association

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

family Voices

National
Stuttering
Association

Changing the lives of people who stutter

In this Issue:

A Sister's Call to Duty

Mara Sunde just turned 18 and she is already striving to make an impact on the lives of people who stutter. She doesn't stutter but it is a topic close to her heart because her little brother Vinny does. Mara has been supportive and protective of her brother but she took it a step further when she decided to turn her senior project into a mission to start Nebraska's first support group for people who stutter.

Mara's hard work paid off and their first NSA TWST meeting on Tuesday November 3, 2009 was a great success. In attendance were 8 kids, who ranged in age from 11 to 17 years old, along with 8 parents and a couple SLPs were able to be there. Mara also invited Tom Shatel, a very well-known local sportswriter for the Omaha World Herald. He has spoken at multiple stuttering events for kids. It was a win-win situation for all who came.

Joanie Cahalan, Mara's mentor said, "Mara did a tremendous job organizing this and doing all the footwork to get this off the ground. She is to be highly commended for her insight and work ethic to do something like this for her younger brother and for teens who stutters."

The NSA interviewed Mara:

NSA: Tell us a little about yourself...

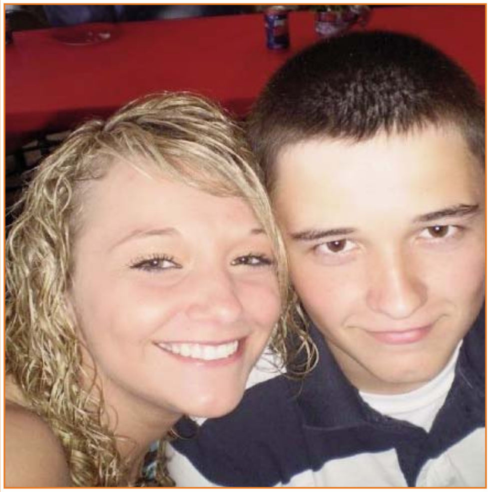
Mara: I like to run cross country and hang out with my friends. I am attending college next August and plan on majoring in English and possibly journalism. I am also interested in speech pathology. I'm just a teenager trying to figure out what she wants to do!

NSA: What is your "story" with stuttering?...

Mara: My story about stuttering is that my little brother Vince has stuttered his entire life. When I was younger I never really noticed his stuttering but as he got older and got into school and he was getting teased. It really affected me. The school we attended never disciplined the students who teased him so I was always "the law" yelling at kids to stop making fun of my little brother. Now that Vince is a sophomore, he has a ton of friends and is very popular.

NSA: What inspired you to start this TWST group?...

Mara: I attend DC West High School in Valley Nebraska and we have a mandatory class called Senior Project. It is a very challenging class which is required for graduation. It includes letters, forms, reflections, research, research and more research!! We have to write an eight page paper and work fifteen hours of a physical project. I chose to start this TWIST group because of my little brother Vince. I thought about what would help him and give him more confidence. So I started to research and found that there were no support groups in Nebraska.



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info@WeStutter.org • www.WeStutter.org

SAVE THE DATE!

July 7- 11, 2010

NSA Annual Conference

Cleveland, OH

The NSA conference will rock your world! Invest time with your family to explore, learn, network and share stuttering with leading experts who specialize in working with children and adolescents who stutter, as well as with other families.

Bring the whole family! Parents, children who stutter (ages 8 and older) and their siblings can participate in activities and workshops which will enrich the whole family.

Ask The Expert

Walter H. Manning, Ph.D., Professor,
The University of Memphis

I have always been uneasy about being termed an expert. My history of stuttering and several decades of experience assisting those who stutter as well as researching and writing about stuttering helps to inform me about the nature of stuttering and making clinical decisions when assisting others. However, there are many aspects of stuttering for which I don't have answers. In addition, every person I see provides a new story and many times I'm not certain about the direction and timing of therapy.

1. Are there specific kinds of stuttering therapy techniques that are best for specific kinds of stuttering?

With a few exceptions, therapeutic protocols for stuttering are not all that specific. Some clinicians emphasize modifying the speaker's pattern of stuttering while others focus on creating and expanding fluent utterances. Most clinicians employ combinations of both. The majority of stuttering takes the form of developmental childhood stuttering rather than the much less common disfluencies associated adult onset due to neurological and psychological (e.g., conversion neurosis) etiology.

Many individuals receive great benefit from desensitization activities which are often necessary before the speaker is likely to have any success in identifying, varying and modifying the form of their stuttering. Other speakers require less desensitization. A basic question for the clinician throughout therapy process is "What does this person need from me now?" The answer will vary according to many factors including the person's age, the nature of their stuttering, and to what degree stuttering influences (often restricts) their daily decision making. Counseling for the speaker, and for a child, the parents, is a basic aspect of any comprehensive treatment protocol. The techniques employed within and beyond the therapy setting are also influenced by the motivation and assertiveness of the speaker as well as the involvement and support of family members, teachers, and friends.

2. Is stuttering hereditary? If so, then why is my child the only one in our extended family that stutters?

Although it is often the case that stuttering runs in families there are many instances where no other individuals in the family stutter. In my case, for example, none of my parents and grandparents or any my three children stuttered. Dr. Dennis Dranya Chief, Section on Systems Biology of Communication Disorders Laboratory of Molecular Genetics at NIDCD/NIH has indicated that, like many human conditions (such as hearing loss) about half of all stuttering is associated with genetics. There is likely a combination of additive genetic factors that make it likely that stuttering will occur and as well as whether or not stuttering is likely remit or persist. In other cases, there is no reported occurrence of stuttering in the family possibly suggesting that there is less genetic loading for stuttering. Genes "express" themselves via their signature proteins only through the interplay with the environment. Thus, both one's heredity and the environment play a role at a ratio of approximately 70% for hereditary influences and 30% for environmental factors. Even for individuals who are part of a family tree that contains a number of individuals who stutter good treatment can have an extremely positive influence.

3. What would I look for when finding a speech therapist for my child?

This is a great question and one that requires a long answer. I'll provide a short one by saying that there are a number of investigations across several clinical fields (including fluency disorders) that indicate that the quality and expertise of the clinician is a major influence on the likelihood of a successful treatment outcome. This has been found to be the case regardless of the therapeutic protocol being used. This is the primary reason why, in each of the three editions of my text, I devoted the first chapter to clinician, expertise, attributes and skills.

If I had to select only one quality of a good clinician it would be the thorough understanding of the stuttering experience by the clinician. Two people who have taken a similar journey are more likely to be connected because of a shared understanding of the experience. Whether or not the clinician has a history of stuttering he or she should understand the breadth and depth of the experience of stuttering. I know many fluent clinicians who do.

I would also seek out clinicians who have a passion for and have enjoyed success assisting those who stutter. I would look for someone who is willing to first do what they ask their clients to do.

4. Is there any correlation between ADHD and stuttering?

Most children who stutter do not have ADHD. The co-occurrence of ADHD and stuttering has been estimated as low as 4% and as high as 25%. There has been some discussion about the

Continued on Page 7

What Can I Say

by Jessica, Naperville, IL

Hi. My name is Jessica and I received a Scholarship to attend this year's NSA conference in Scottsdale, AZ. I experienced the most amazing thing in my entire life. I had such a great time and will never forget the people I met.

I've never been so outgoing in my life and I've never felt so proud to stutter in my live either. I'm forever thankful for this scholarship and all of the people who made my experience what it was. I learned so much and I can finally stutter a little easier, even around my family.

During the closing ceremony, my mom, someone who has never been very open about my stuttering, started tearing up. I was so shocked that by the end I was crying and my mom and I now have a stronger relationship and can talk about anything. I was nervous on the plane ride to Arizona because I didn't know what to expect. But now I can hardly wait for next year.

Last year in school I took a creative writing class because I love to write. We did a unit on performance poetry. When writing performance poetry, you are supposed to be truthful and vulnerable, so I thought, "what is more truthful than writing about my stuttering?!" I shared it with my class and everyone loved it, including me. My speech pathologist hung it up in her room, and so I thought I would share it here. I hope it is motivational for others. Thanks for everything!

What I Can Say…
I find it more a gift than a curse
I'm different, I'm special, I'm unique
I open my mouth, and the words don't come out

The walls are caving in
I take a deep breath
Search for the strength

I long to be normal
And am proud to be different
I've had it since I've been born

It's apart of me, in my blood
I tackle my fear
Speak my mind

I'm important
I matter
I speak and speak
And stutter and stutter

It feels good
I feel free
It's not about what I can't say
But what I can say

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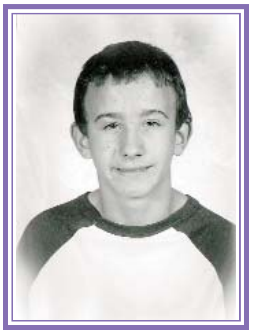
Teens Who STutter

Spectacular Speech and Language

by Paul, Delevan, NY



I'm sure you have heard about President Obama. Have you heard about Joe Biden? Joe Biden is the Vice President. Did you know that in Joe Biden's young life, he had some trouble in school? He took speech therapy because he had a little bit of trouble speaking. He took classes on speech therapy to get some information to make his stuttering better. In his own words, he said, "It's a funny thing to say, but even if I could, I would not wish away the darkest days of the stutter. Carrying it strengthened me and made me a better person."

How come Joe Biden had trouble in his young life and how come now he is the Vice President? Because he never let it bother him in any way shape or form. That means that if you have any problems in school or out of school, don't let it get to you. Don't let people put you down or make you feel like a bad person. That could turn you towards the bad road. That will mess up your life. Just pick the friends that will guide you and help you to get through life. Also, you have to keep on trying like Joe Biden did and you will be successful like him.

PANTHER PAGE 7

Spectacular Speech and Language

Spectacular Speech and Language

By: Paul Horn

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Happy New Year!!

by Debbie Nicolai

It's hard for me to believe that another year has already come and gone as I sit here writing another New Year article.

As I am sure many of you know, in February I will be retiring from the NSA Board of Directors after six years. Marybeth will be alone as the Family Programs chair until we find a replacement for me to join her and Sarah will continue as the Family Programs Administrator. I have no intentions of dropping out of the picture and I will continue to be a part of the NSA and I will always be available to all of you for support, answers or just plain ole chat!

The past six years have gone by so quickly and I have loved every second of them and I have so many memories to take with me.

When I first joined the Board at the Nashville conference, I had no idea what I was getting into. Nina Reeves was my mentor and I couldn't have done anything without her guidance, knowledge and love. Nina's commitment to the NSA and to the parents, kids and teens who stutter is apparent in everything that she does and she continues to be an inspiration to me.

The Family Programs portion of the conference has tripled in size over the past six years and it blows me away each year at the Orientation when I see so many new families as well as so many of my old friends sitting in the audience. It is overwhelming to me to know that I have been a witness to the growth of our program.

My favorite part of being the Family Programs co-chair was being able to meet a child, a teen or a parent for the first time at a conference and then watching them during the conference as they opened up and realized that it is OK to stutter. The kids who walked in to the orientation not wanting to speak and then to seei them running through the halls with their newfound friends laughing and chatting loudly. The teen that wouldn't say his name then a short while later I see him sitting in a workshop telling stories of his stuttering journey. The parent that realizes that their child is going to be OK and can do anything that they want to do and I know that their tears are real tears of joy and pride.

I have been able to watch my daughter, Stephanie, grow from an unsure 13 year old to a confident 20 year old. I know that her strength and confidence is because of the NSA and the wonderful people of the NSA that we have met over the years. Each of you has brought so much to our family and I hope that I was able to bring something to yours.

I have a new project that I am working on and I hope that as your child grows up, that he or she will become a part of this new program. This project is the step between teens and adults and is focused on the "Twenty-Somethings" of the NSA. This program will be set up very differently from the Family Programs and I am looking forward to getting it started and watching it grow quickly.

I want to say thank you to all of you for all of your help, friendship, love, and support over the years. It was a joy to do this job and to meet all of you. If you are going to be in Cleveland, please set aside some time, I would love to sit and chat with you. Thank you for this opportunity and for putting up with me!

A special thanks to Tammy for all of her support and help as we worked on the conference each year. To Marybeth for her calm against my crazy and to Sarah for all of her work, dedication and ideas. I am excited to see where you take this! To the past and present TAC members that have put up with me over the years, you are all such amazing people. I am blessed to have been able to have worked with you and gotten to know you. xoxo

Love to you all, and remember - "You are not alone," we are all in this together.

EDITORS NOTE: Thank you Debbie! The NSA cannot say enough to thank Debbie Nicolai for all that she's done. Her hardwork, love and support has been unbelievable. She began her journey with the NSA to help her daughter Stephanie but she ended up doing so much more. She has impacted the lives of hundreds of kids and teens who stutter and their parents. Debbie made her mark on this organization that will never be forgotten.

Twenty Somethings

NEW focus for 2010 NSA conference: making the transition from teen to adult involves all sorts of new challenges. We now offer workshops and activities planned specifically for our "Twenty Somethings" and their parents.

Hope, Confidence and Happiness

by Melissa and Brandon, Artisia, CA

Hi there! I know the conference was over a month ago but I have not gotten a chance to thank you directly for everything you did for us this conference. We couldn't have been more blessed than to attend this year's conference! My son, my sister in law and I are still raving about how great of an opportunity it was.... When we got back from the conference we had so many stories to tell our family and friends, along with very good information on stuttering that we all learned during the conference. Not only did this experience help me as a parent to understand stuttering, but it gave my son hope, confidence, and happiness knowing that he isn't the only one in this world who stutters! We are looking forward to next year!!!!!

Stutter Buddies

Second Time Around

by Olivia, Tacoma, WA

This year was my second time at an NSA conference. It is fun. I like meeting new friends and the food they have. I like the gift shop.

It's good to know you are not the only person who stutters.

National Stuttering Association

Arizona Conference

by Dustin H of Broadview, OH

I like this convention because I made friends and their families. I like meeting other people who stutter. I like all the workshops because we do the games. I like living in Arizona because my cousins live here.

Touchdown!

by Hunter, Richmond, VA

I play football. It is fun. Last year, we made it to the first round of the playoffs.

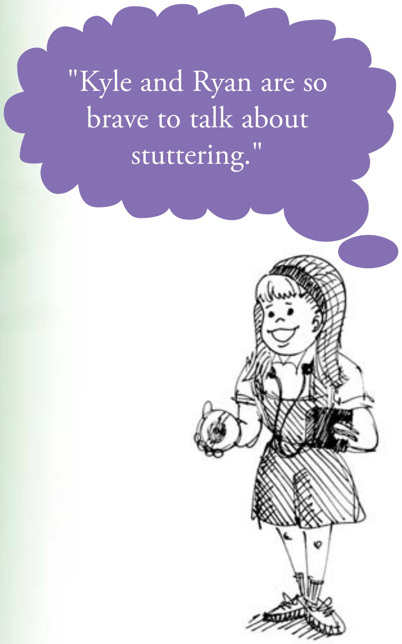
I play defense and offense. P.S. Don't be afraid to play sports because you stutter.

Stutter Buddies

Speaking in Front of People

by Kyle A., Honolulu, HI

I am a person who stutters. I started stuttering when I was in preschool. Sometimes I am scared to speak in front of a group of people because I might stutter. There are still some times when I don't stutter when I have to speak in front of people.



International Stuttering

by Ryan, Corner Brook, Newfoundland, Canada

My name is Ryan Lowe and I am 11 years old. I am in grade 6 at Sacred Heart Elementary School in Corner Brook, Newfoundland. I am interested in video games, camping and hockey. I recently won "Most Improved Player" Award for my hockey team. I have been receiving speech therapy since I was 3 years old. My speech therapist is Patti. She is very nice.

In January of this year, my Dad and I traveled to Toronto, Ontario, Canada to get a SpeechEasy. It has reduced the number of times I stutter. I feel better when talking in front of my class with the SpeechEasy. Today I did a speech on taking care of your pets in front of the class for a "speak off". It was fun!!!

Sometimes people make fun of me for stuttering. This hurts my feelings so I recently did my Science Fair Project on stuttering and how the SpeechEasy has worked for me. I got 100%!!

I hope people will become more understanding of kids and adults who stutter. That's my biggest wish!

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Changing lives of people who stutter

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

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

cover story cont. from page 1...

NSA: What efforts and time did you put into advertising and promoting it?
Mara: I took the flyer format from Marybeth Allen, NSA Family programs board member and my mentor, Joan Cahalan, and I filled it out and printed them off. She sent them to all Speech Therapists in the Omaha area.

NSA: What are your biggest fears?...
Mara: My biggest fear in life is that I won't make my parents proud and I will not be successful. But I know that if I keep trying hard I will do just fine.

NSA: What are you r biggest accomplishments?...
Mara: My biggest accomplishment would be getting runner-up in state powerlifting. I can honestly say I am the second strongest 123 pound girl in the state of Nebraska!

NSA: How does your family and friends react to stuttering?...
Mara: My family is so supportive when it comes to Vince's stuttering, everyone is patient with him and never even has a reaction to it. Sometimes we forget he even stutters, we're just so used to it.

NSA: What are you looking forward to the most about having this group avail for people who stutter?
Mara: The thing I look forward to the most with this support group is that I helped these kids find each other. I helped them meet other kids just like them. I like to think I made these kids' lives a little bit better.

NSA: What does it mean to you to be able to talk to other people about stuttering and be supported?
Mara: Well since I don't stutter it doesn't have that big of an effect on me, but I can see what it does for my little brother. He was so happy at that support group and he's very thankful that this was started. Support groups help kids more than people know.

For more information on this group, contact the NSA or the group's leaders (Teen Leader) - Mara Sunde, marasunde@yahoo.com (Parent Sponsor) - Al Tarrell, 402-850-0581, aetarrell@cox.net (Parent Sponsor) - Kena Tarrell, 402-871-8425, maria.tarrell@cox.net.

"Ask the Expert"cont. from page 2...

commonalities that exist among some conditions that involve executive function or regulatory activities associated with the basal ganglia in the central nervous system but there is no direct connection or strong correlation between ADHD and stuttering that I am aware of.

5. I know that the amount of stress my child is under affects his stuttering. Especially at the end of the term when finals are approaching. What can I do to help him?

Of course there are many forms of stress and children, as well as adults, have very different reactions to the same stressor. For individuals who stutter, time pressure to verbally respond is a common and powerful form of stress that often results in increased frequency and effort associated with stuttering. Whatever the form of stress the child seems to be responding to, systematic desensitization is likely to help. This can be accomplished by working up through hierarchies of increasingly stressful communication situations along with role playing, promoting increased risk taking, and practicing in speaking situations beyond the treatment environment. It is also helpful to develop support systems of important others (parents, relatives, teachers, coaches and friends) who understand the nature of the problem and the rationale for the behavioral techniques being practiced

6. I feel my child has a good therapist and has learned lots of 'tools' to help, but many times he doesn't want to use them and it bothers me. I never know how to react to those situations.

Many of the helpful techniques we learn in life are counterintuitive (e.g., counter-steering when our car is sliding on ice). This is also the case in learning how to alter our situation when stuttering. Voluntarily stuttering (giving yourself permission to stutter) often results in less real stutering. In addition, the "tools" for altering the form of stuttering (e.g., pull outs or easy outs) or achieving fluency (e.g., slowed speech, light articulatory contacts) sound and feel funny to the speaker. As unpleasant as the stuttering is, it is something you are used to while the new way of speaking takes concentration.

It is first necessary to achieve some level of desensitization about stuttering in order to employ the new techniques that are necessary to modify the way we speak, especially beyond the therapy environment. The child, as well as parents, relatives, teachers, coaches and friends, need to understand the rationale and meaning of these changes and provide understanding and support.

It is also important to appreciate how a technique needs to be practiced hundreds of times, both in easy and more stressful communication situations before one is able to confidently rely on the technique. The clinician or other clients can model the techniques (video tapes from the Stuttering Foundation can be helpful here). It is important to appreciate that in the early stages of treatment the primary reason for using the techniques is more about the speaker's ability to take charge of his or her speech mechanisms rather than achieving natural sounding and spontanious fluency.
As the child (or adult) begins to understand that he or she really does have some options about altering their pattern of speaking rather than reflexively pushing harder or running and hiding from stuttering things begin to change.

Walt Manning is a professor and Associate Dean in the School of Audiology and Speech-Language Pathology at The University of Memphis. He received his bachelor's degree from Lycoming College in Pennsylvania in 1964, his master's degree from Penn State University in 1967, and his doctorate from Michigan State University in 1972. He has published more than 70 articles in a variety of professional journals and has presented on many occasions to regional, national, and international meetings. NSA awarded him Speech-Language Pathologist of the Year 2009. email: wmanning@memphis.edu

2009 NSA Family Programs - Growing by Leaps and Bounds

JULY - Dallas In July, the Dallas meeting had 8 people in attendance, including a “hopeful” new leader for the group. We discussed the concept of “WHAT IF” and utilized a handout that lead participants to discover what they thought might happen if “tomorrow everyone woke up and realized that it truly WAS OK to stutter?”! In other words, what would happen for each person if stuttering became just another way of talking in society? This was a fabulous discussion, as each member shared what difference this might make in their thoughts, feeling or speech and communication.

AUGUST - East Bay, CA Chapter. After the convention in Scottsdale last month the energy and motivation to build our local chapters in the Bay Area and create a new TWiST Chapter really started to take off. Along with Michael Sugarman, Nina Ghiselli, Mike Garcia, 3 events were planned for outreach through the end of summer and into October. The first event was Saturday, August 22nd in Hayward CA, and was a "bi-lingual" event for all ages featuring activities and presentations on stuttering in both English and Spanish. The event was a rousing success with 19 people in attendance! The other two events were both in October and included an International Stuttering Awareness Day conference on October 22nd including presentations from Michael, Nina, and Mike, as well as Josh Denault and Vanna Nicks. The Teen Open House on October 17th had over 30 people in attendance, gathering to meet and talk about stuttering with teens and their families. All of these events and more are detailed on the Bay Area’s website at http://www.bayareansa.com.

OCTOBER - Phoenix Metro NSA Kids/NSA TWiST had their first meeting ever on Saturday, October 24 with a great turnout of 40 people including the 4 co-leaders: 6 Kids, 3 Teens, 10 parents, 7 siblings, 5 SLPs, 6 SLP grad students and 3 others(two adult PWS and a friend)! The meeting was started by a showing of Michael Sugarman's video ‘The Faces of Stuttering’ and general introductions, followed by three separate breakouts planned for the Kids group, the Teen group and the parents.

The Kids group, led by D'nell Rynd and Margo Berkowitz made stuttering monsters out of paper bags. When they were done, Sarah (10 years old) initiated the game "Telephone". Afterward, the group played Stuttering Jeopardy, which was MC'd by Jack (also 10 years old) and Sarah. They did an awesome job and you could tell all the kids loved the game!! Later, one boy asked D'nell if he could come to this meeting every day!

The Teen group consisted of three boys, several SLP grad students and two SLPs. We talked about why we were at the meeting and played a couple of ice breaker games (Two Truths and a Lie and Human Bingo). We also talked about what the purpose of and ideas for the teen group. The members of the group (teens and grad students) had an opportunity to anonymously write down their expectations and ideas.

Meanwhile, Lynne Remson led a roundtable for the parents where they discussed issues important to them, asked questions and shared concerns. Also included were a couple of adults who stutter that shared information as well. We heard great feedback from parents about how helpful this was for them!

Parents, kids and teens meet across the country to support each other. Check the NSA website for a group in your area.

NSAKids and TWST GROUPS...
- Dallas, TX
- Mesquite, TX
- Rochester, NY
- Low Country, SC
- Lafayette, LA
- Sacramento/Roseville, CA
- Chicago/Naperville, IL
- Illinois State University, IL
- Chicago/Skokie, IL
- Orlando, FL
- Auburn, NH
- Southeast, MI
- Milwaukee, WI
- Queens, NY
- Rockville, MD
- Ft. Lauderdale, FL
- Houston, TX
- Omaha, NB
- S.F. Bay Area, CA
- Northern Virginia
- Phoenix/Scottsdale, AZ

UP & COMING GROUPS...
- Long Island, Nassau Co., NY
- Long Island, Suffolk Co., NY
- Brooklyn College , NY
- Tampa , FL
- San Diego , CA
- Baltimore , MD
- Syracuse, NY
- South Bend, IN
- Honolulu, HI
- D.C. area

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.

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