

# Family VOICES

Celebrating 35 Years of  
Changing the Lives of People Who Stutter

FOURTH QUARTER 2012

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## Mothering a Son Who Also Stutters

JENNY STRIPLIN, CA



As a person who has stuttered for most of my life, one would think I'd have given at least a fleeting thought to the possibility of having a child who also stuttered. Looking back, I'm surprised that I wasn't prepared for this likelihood, but somehow it just didn't cross my mind. It had to be because I truly had no idea about the strong genetic component associated with stuttering until somewhat recently. So when my son Matthew, began showing signs of stuttering between the ages of two and three, I was convinced that he was emulating the dysfluent speech patterns that I was using rather than beginning to manifest characteristics of a true speech disorder. Since he didn't seem bothered by his speech, I didn't bring it to his attention or seek professional services. Similar to many young children who exhibit early speech dysfluencies, I firmly believed that he would eventually outgrow his stuttering.

It wasn't until Matthew was about eight years old that I realized he wasn't outgrowing his stuttering

like I had anticipated. Aside from noticing an increase in his speech struggles, he was becoming bothered by and aware of his dysfluencies to a greater extent. This became especially apparent one afternoon when he caught me completely off guard by saying that he didn't want to participate in any of his regular sports or activities. He was adamant about wanting to stay home and only work on school assignments (he was homeschooled at the time). I was absolutely stunned by that comment, as what active boy only wants to do school work? He had decided then that he no longer wanted to play baseball, football, or basketball, compete in chess tournaments, or return to taekwondo to work toward his 3rd degree Black Belt. I was very confused and wondered what brought this on. It took me a while to get it out of him, but finally, he broke down crying and tearfully asked me, "Mom, what's wrong with me? Why can't I just talk like everyone else?"

Eventually, Matthew acknowledged that the reason he didn't want to be around anyone but family was because of the teasing and mimicking that was coming from other children. They would ask him questions like, "W-w-why do you t-t-talk like that?" or try to get the other children to laugh by imitating his stuttering. These comments thoroughly devastated him as he had absolutely no idea why he stuttered and he wondered aloud if it was because he was "stupid." As a mother, hearing that my kind, loving, and usually happy child was being ridiculed and insulted by others just broke my heart, but as a mother who stutters, I felt dreadfully overcome with guilt as I "knew" that I was completely responsible for bringing this heartache and despair into my son's life.

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

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Be sure to check out 'WeStutter' on Facebook and Twitter today!

# Ask the EXPERT

WALTER H. MANNING, PH.D.,  
PROFESSOR, THE UNIVERSITY OF MEMPHIS



*This article was originally published in the Nov/Dec 2009 issue of Family Voices. Because the subject matter is so pertinent, we have decided to republish. We hope you enjoy!*

## **Q :: Are there specific kinds of stuttering therapy techniques that are best for specific kinds of stuttering?**

**A ::** 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 dysfluencies associated with 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 in the case of 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.

## **Q :: Is stuttering hereditary? If so, then why is my child the only one in our extended family that stutters?**

**A ::** 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.

## **Q :: What should I look for when finding a speech therapist for my child?**

**A ::** 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.

**Q :: Is there any correlation between ADHD and stuttering?**

**A ::** 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 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.

**Q :: 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?**

**A ::** There are many forms of stress, and children, as well as adults, can have very different reactions to the same stressor. For individuals who stutter, time pressure to respond verbally is a common and powerful form of stress that often results in increased frequency and effort associated with stuttering. Whatever 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.

**Q :: 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.**

**A ::** 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 stuttering. 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. 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 spontaneous and natural-sounding 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.

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**Walt Manning**

*Walt 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](mailto:wmanning@memphis.edu)*

## Finish That Sentence!

In Sarah Onofri's *Finish That Sentence* workshop at the 2012 Annual Conference in St. Petersburg, the kids of the NSA were asked to finish the following sentences regarding their speech. Read below to see what they had to say!

### When someone makes fun of someone who stutters, I can say...

- ...That's mean.
- ...Don't laugh at him because he's different.
- ...Don't say that, you're being a bully.
- ...Don't say that, it's how God made them.
- ...Think about what it might feel like to stutter.
- ...I do not like it.
- ...You should know about the NSA and stuttering.
- ...Let him be, because it's who he is.
- ...Can you please stop laughing at me just because I stutter?



## Stutter Buddies

Family Programs is fortunate to have participants from the Intensive Fluency Group at Buffalo State College contribute to Family Voices in our Stutter Buddies section. Look here for articles from these brave and amazing young people! ::

## What I Know About Stuttering

SYDNEY, NJ

There are many reasons why people stutter. Some people start stuttering at very early ages. Stuttering is worse for some people when they talk too fast. Stuttering can also happen more when the person who is stuttering needs more time to plan their ideas.

These are some types of stuttering that I will present to you. Repetitions are a type of stuttering where you repeat over and over again what you are saying. Prolongations are another type of stuttering that happens and is when you stretch your words accidentally. A block is when you can't get your words out of your mouth.

If you stutter, there are some strategies to help you. Cancellation is a strategy where you stutter, but then you pause for a few seconds and do a purposeful prolongation. Slide in is another strategy, but it is a purposeful prolongation by itself if you think you are going to stutter. Slide out is like cancellation but you don't pause between the stutter and the slide in. Continuous phonation is like a slide in, but it's more to string your words together. Pausing is a strategy that you might know to help you stop and think about what you are about to say. Light contact is when you try not to press your lips or your teeth together too hard when you're talking.

If you want to know about the myths about stuttering, you've come to the right person. One myth is that stuttering is caused by nervousness. It can happen more when you're nervous, but it is never caused by nervousness. Another myth is that people who stutter cannot be president because there are more important parts to being president than your speeches. Another myth that people believe is that people stutter to get more attention. When you are young and you want to get attention, you might stutter. However, wanting attention is not the reason you stutter.

Now you know more about stuttering! ::

July 24, 2012

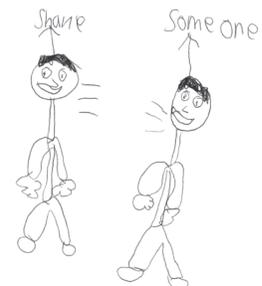
Dear Stutter Buddies,

My name is Shane. I am eight years old. I am going into the 3<sup>rd</sup> grade at Forrest Elementary School. I live in Williamsville, NY. My favorite show is *Sponge Bob Square Pants*. I am a person who stutters, and I have learned ways to speak easier. Some of the ways are: easy onset and light contacts. Easy onset is slowly turning your voice up, and light contact is "tip toeing" with your speech helpers. I won't let stuttering get in my way of being successful and neither should you.

Your friend,

Shane

Shane





## Staying Connected

STEVE ERNST, MD

question or add something to the conversation. There is a host to lead the discussion; in my first experience, Miranda Smith and a few guests talked about New Year's Resolutions related to stuttering. Since then, there have been shows for both teens and parents that covered topics like applications, going back to school, helping your child who stutters, dating, and many more subjects about which I learned a lot just by listening.

I'm now one of the co-hosts of the NSA Family Radio, and I'm enjoying it a lot. I've discovered how much I benefit from hearing how other people who stutter deal with tough situations and realizing that we all share similar experiences. I learn about both the guests on the show and myself. If you could see me before a show, I'm nervous about my speech and trying to ensure I'll make sense on air. However, I use it as a challenge each month to face my fears and do what I need to do. I start talking, and I already feel accomplished and comfortable knowing that I am among friends who know exactly what I'm feeling. It's always exactly what I need to hear each week to keep being comfortable with my speech and my role as a person who stutters.

I get so much out of the NSA Family Radio show, and I'm confident that everyone that listens feels the same way, so I welcome you to join us! I invite you just to listen, and, when you are ready, we would love to hear you live on air. ::

In the wake of my second NSA conference this year, I found myself missing all of the friends I had made over the four days in St. Petersburg. As anyone that has attended a conference knows, you instantly have a connection with everyone around you. I wanted a way to make the conference last all year, if possible! While I'm fairly certain it wouldn't work to have a year-long conference, I think I've found the next best way to keep in touch with the stuttering community: the NSA Family Radio shows.

The first time I participated in the radio show, I found that it was really easy. At the start time, I used my phone to call in at (310) 807-5072, and from there I listened and, once I was comfortable, I could ask a

## Teen TALK

## TAC News

MIRANDA SMITH, TAC CHAIRPERSON

Adjusting to life after the amazing 2012 NSA conference, starting school, moving away to college, working, and being involved in school activities have just been a few of the things that the teens of the NSA and the Teen Advisory Council (TAC) have been busy doing, but things are about to get a lot busier! The TAC would like to welcome two new members to the council – **Eddie Brown** and **Dan Haus!**

The TAC will be very busy this coming year with projects that involve advertising stuttering in their community, fundraising for the NSA, being proactive for the upcoming International Stuttering Awareness Day, and of course, planning and thinking ahead for next year's conference in Scottsdale, Arizona!

The NSA Family Radio shows have been an awesome resource for teens who stutter. We have received incredible feedback from the teens of the NSA, and will continue to schedule shows throughout this coming year.

Looking for something else to look forward to while you are anticipating for the 2013 conference? Keep an eye out for the *NSA TwiST Live!*, an interactive tool for teens who stutter – provided by Google+ Hangouts – which will allow us to do a video chat with up to ten teens at one time. We can talk about stuttering, our daily lives, and just relate to others who stutter and who go through the same things we do in middle school, high school, and even college! We hope to have *NSA TwiST Live!* up and running soon, so keep an eye out to join in on the fun! ::



## Chapter Spotlight :: Raleigh TwST

The Raleigh TwST chapter met for their regular meeting in August, the last meeting before many of the families start the school year. The group took this opportunity to dive in to goal setting and to break down their goals into easy-to-achieve, measurable parts for a day or a week. The group agrees that this gives them solid successes that they can celebrate as they move along their individual roads. The discussion turned towards advertising and disclosing their stuttering to teachers and counselors, a topic of discussion also had within the group earlier in the summer. Since many members were fresh on the heels of the NSA conference in St. Petersburg, FL, and Chapter Leader Reuben Schuff had a copy of Bill Wade's Keynote speech and a laptop with DVD player, the group was able to watch a clip from Bill's address about confident disclosure and 'owning the elephant in the room'. The message went hand in hand with the evening's discussion and message of confidence and goal setting. Reuben had a few extra copies of Bill's speech on DVD, which are now in the hands of several families. Reuben feels like the message of confidence and successful communication from the NSA Annual Conference was really brought home this month, and thinks that it is a fabulous resource to have parts of the Annual Conference to bring back to the local chapter!

—Reuben Schuff



### A Special Thank You

The NSA and Family Programs would like to recognize and thank **Shannon Beaty** for her contributions of leadership and support to teens who stutter and their families. Shannon

recently stepped down as a Chapter Leader of the Dallas, TX TwST chapter which she led for four years. Because of Shannon's leadership and dedication, the Dallas chapter has become one of the most successful Family Chapters within the NSA. All who have been touched by Shannon and her generosity have most certainly had their lives enriched as she leaves an indelible impression on everyone she meets.

The Dallas TwST chapter remains active under the very capable leadership of **Tricia Lehrman** and **Clint Bounds**, with the assistance of **Jeff Miller** and **Melissa Greear**.

## A Message from Family Programs

PATTIE WOOD, FAMILY PROGRAMS CHAIR



As I write this article, I am still reliving the wonderful memories of another successful NSA Annual Conference. Reconnecting with great friends, meeting new ones, and seeing my son, Danny, gain more confidence in being with his friends who also stutter is always the highlight of our summer. Speaking with many of you since we have all returned home has been great. My favorite part of Conference is meeting new families and staying connected throughout the year. It makes waiting for next Conference a little easier!

Now that we are all getting back to school and our normal routines, the holidays will be upon us before we know it. I know for us, the holidays bring about many changes in Danny's speech. The excitement of the season along with the numerous get-togethers can be stressful for all of us, but especially for our children who stutter. Trying to carve out down time is difficult, as is explaining to well-meaning relatives things about stuttering and how they can be helpful during this extra busy season. Each year gets a bit easier and we have learned to talk openly with Danny and our family, which seems to help our holiday functions go more smoothly. It also helps to stay connected with our NSA friends who are a great source of support. If you aren't already a member of the NSA Parents Facebook page, be sure to join. This is a great place to talk with other parents and share your ideas or get feedback and support. I know that being part of the NSA Family for the past five years has gotten my family through many difficulties while also sharing in our successes.

Though it seems far away, now is the time to start thinking about the 2013 Annual Conference in Scottsdale, Arizona. The hotel and area are gorgeous and it is going to be a great time! I hope to see all of our first-time families back again next year. Information is on the website, and reservations can be made at discounted rates through February 13, 2013. As for now, I wish all of you a wonderful upcoming holiday season! ::

## Join Us for NSA Family Radio

Your Virtual Family Chapter for Parents, Kids, and Teens!



NSA Family Radio is hosted by the Family Chapters Committee of the NSA. The mission of the show is to bring together kids and teens who stutter and their parents, siblings, and other family members in a way that is convenient from all over the world! We will be sharing ideas and information, as well as providing support. Best yet, you can join us for a live conversation as the show allows you to call in and participate. In addition, all shows are recorded and archived if you can't catch us live. For dates, times, and upcoming show schedules, please visit [www.westutter.org](http://www.westutter.org). JOIN US LIVE! Call (310) 807- 5072 or toll free number: 877-560-5873

# Get Ready for Conference 2013!

STEPHANIE COPPEN, FAMILY PROGRAMS ADMINISTRATOR



Since the close of the NSA Annual Conference in St. Petersburg, FL, Family Programs has been hard at work planning for the 2013 Annual Conference in Scottsdale, AZ. Our goal is to make each conference better than the last, and we could not do that without your feedback, so we would like to thank everyone who completed the 2012 conference survey. The responses and results allow us to view the conference experience from a different perspective and provide us with insight on how we can improve the conference for you, your child, and your entire family.

Don't forget that registration for the NSA Annual Conference in Scottsdale, Arizona, July 3-7 at the beautiful Westin Kierland Resort & Spa will open in January 2013, just a few short months away! Hotel reservations are already open at a generously discounted rate, and will sell out quickly, so if you haven't done so already, now is the time to reserve your room. Please visit [www.WeStutter.org](http://www.WeStutter.org) for additional reservation information.

Once again we are offering scholarships assistance to families in need who wish to attend our Annual Conference. Please contact our National Office at (800) WE STUTTER (937-8888) or [Info@WeStutter.org](mailto:Info@WeStutter.org) for additional information.

As always, if there is ever anything the NSA and Family Programs can do to assist you, please don't hesitate to contact us. Remember, you are not alone!

See you in Scottsdale! ::



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Sadly, it was during this time that my speech was the most dysfluent that it ever was, and I had no choice but to move from being a covert to overt person who stutters. My husband, whom I've known since I was 16, and even my parents, were extremely shocked and puzzled upon hearing my stuttering reach a truly debilitating level of severity.

It was horribly frustrating and profoundly terrifying as I could hardly speak and struggled to even pronounce initial word sounds, letters, or numbers. I felt as though I was continually being choked and living a recurring nightmare where I needed to scream for help and just couldn't utter the word to save my life. Instead of just getting stuck on various sounds and stuttering through a word like I usually did, I was blocking for the first time ever. Often, I had to repeat entire phrases multiple times simply so I could eventually squeeze out a word or even a sound—and that was on a good day! Most of the time, however, I wound up trying my absolute best to spell words, having others guess what I was trying to say, or even resorting to using sign language with my family, utilizing some of the basic ASL signs I had learned when Matthew was a baby.

At this point, I was feeling entirely hopeless about my own stuttering, so one can imagine the devastation I felt about Matthew's escalating speech struggles. The enormous sense of guilt I felt was compounded by the knowledge that I should have obtained speech therapy for him when he was younger or at the very minimum, and perhaps brought my own stuttering out in the open. That way, he could have turned to me when he was first faced with his own questions or concerns about his stuttering, knowing that he had a caring and supportive mother who would listen to and sincerely understand his unique communication challenges.

Additionally, I wish that I had been able to offer him a basic understanding of our specific speech disorder. The problem was that even I didn't know much about my own stuttering, in particular, why it occurred. What I did know was that it was a shameful habit that I had been trying to break for as long as I could remember. "Jenny, just slow down; think about what you want to say before you say it; enunciate each word when you speak."

Fortunately, it was during this most distressing period that Matthew's supervising teacher was growing increasingly concerned about his speech struggles and gently suggested that we seek a speech assessment for him from the school district. Just prior to

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this conversation I had initiated my own search for a local speech pathologist who was experienced with stuttering. However, I was waiting to make an appointment for Matthew until I somehow regained at least a semblance of my former, more fluent speech. Frankly, I was terribly worried, as most of the time I couldn't even utter my name or phone number, and I loathed the humiliation I felt after such an encounter. Slowly, I was working toward gaining the courage I needed in order to get Matthew the help that I now knew he required.

Beginning the acceptance process was something I should have done years ago, but knowing that I had to be an example for Matthew really propelled me forward.

Advertising my stuttering to others was previously unimaginable, but now I wanted him to see that he shouldn't be ashamed of his speech struggles and instead, use any opportunity he could to educate people about stuttering. This really seemed to help him become more accepting of his stuttering, and from the beginning, his wonderful school speech pathologist has been very supportive and encouraging. With her guidance, he finally began to understand more about his stuttering and soon learned various techniques that he could use to smooth out his speech. He also started to become more assertive about his stuttering and when confronted with teasing from classmates or teammates, he would simply say, "So what, I stutter, what's the big deal?"

Remarkably, we both reached a pivotal point with our stuttering around the same time. Openly discussing Matthew's stuttering with others in order to ensure he received the speech therapy he needed helped me to become more accepting and candid about my own speech challenges. It also seemed to lessen the sense of shame and isolation that I had been holding onto for decades. With this newfound confidence, I finally sought out speech therapy and a stuttering support group for myself.

Interestingly, our respective progress and acceptance seems to be intertwined. There continues to be a direct relationship between me becoming more authentic and secure with respect to my own stuttering and Matthew developing more of a willingness to confidently discuss his speech challenges at home and with others. I have learned so much from him, such as how to laugh at my stuttering and not take myself too seriously. We

have also become much more patient when listening to one another, as well as to other people who stutter and even to those who don't. Ultimately, the most important lesson I have learned, as a mother of a child who stutters, is to listen to what it is that Matthew is trying to communicate to me rather than focusing on the manner in which he says it.

Matthew is becoming such a remarkably assured young man and I feel so blessed to be his mother. I now firmly believe that his stuttering will not hinder him in life; instead, I have already seen the way it continually serves as an opportunity for him to develop essential traits such as strength, fortitude, and courage. It certainly hasn't been an easy journey and I realize that it is far from over, but both Matthew and I have definitely come a long way with our stuttering. In a span of about three years, we have both transitioned from letting our stuttering negatively imbue our lives, to achieving the ability to maintain a comfortable attitude of acceptance and hope. ::

## Upcoming Family Events

**November 14-17, 2012 | Atlanta, GA**

American Speech-Language Hearing Association Conference

**December 1, 2012 | St. Petersburg, FL**

NSA End of the Year Gathering  
Renaissance Vinoy, St. Petersburg, FL

Be sure to check [www.westutter.org](http://www.westutter.org) often for newly scheduled events!