

# Letting GO

The Monthly Publication of the National Stuttering Association



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## A Story from Africa

BY JOE LUKONG

### The experience of stuttering is universal

THANK YOU FOR PUBLISHING A LETTER FROM ME in the July 2002 issue of your very informative magazine, *Letting GO*. I am now 37 years of age and have stuttered all my life. Seventeen of my brothers, sisters, half brothers and sisters stutter, too. It would appear that stuttering is hereditary in the polygamous family I hail from.

Since there wasn't any modern speech therapy for stutterers in Cameroon, I went through the available traditional, crude and at times very unpleasant treatments for my stutter. Some of these "cures" consisted of drinking a yellowish liquid substance that comes out of the roots of the rafia palm bush in marshy areas called in one of the dialects of cameroon as kilu. Within the Nso tribe of Cameroon, it is believed that this substance is a good cure for stuttering.

Another method I went through consisted of inhaling through the nostrils a greenish liquid substance that is squeezed from the leaves of the colanut tree and also inhaling the smoke

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• SOME MEMBERS OF SCAC (l to r) BERNARD GHAMSI, MARIA THERESA, JOE LUKONG AND NESTOR CHIM.

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## The NSA Wins ASHA'S Distinguished Service Award

Over recent years, we have seen a significant growth in collaboration and partnership between people who stutter and speech therapists. In countless ways, this collaboration has been bearing fruit. Now, we are pleased to announce that the American Speech-Language Hearing Association (ASHA) has recognized the efforts and accomplishments of the National Stuttering Association by awarding us one of its highest honors.

The ASHA Distinguished Service Award (DSA) recognizes individuals or organizations outside of ASHA that have made a meaningful contribution to the field of speech-language pathology. According to ASHA, recipients of the DSA have had a significant impact on the Association and the profession in one or more of the following areas: (a) consumer advocacy, (b) governmental affairs, (c) public awareness, (d) research, and (e) service to the Association. ASHA's recognition of the NSA in this manner

marks a significant step in highlighting the growing cooperation between the professional association and our organization.

The nomination proposal was prepared by Nan Bernstein Ratner (coordinator of ASHA's Special Interest Division for Fluency Disorders). Several prominent members of the professional community also contributed to the document. We are grateful to everybody who participated in this nomination!

The proposal details how the NSA has made major contributions in, not just one key area, as required for this award...but in all five areas! Since many of you are not familiar with the full scope of the NSA, we thought it would be enlightening to publish the entire text of the nomination packet.

We are grateful to everybody who participated in this nomination, and we look forward to receiving this prestigious award at a ceremony held during the Annual ASHA Convention in Atlanta, GA on November 22, 2002.

#### INTRODUCTION

The purpose of this document is to nominate the National Stuttering Association (NSA, formerly the National Stuttering Project) for ASHA's 2002 Distinguished Service Award. The NSA is the largest support group in the U.S. for people who stutter. This year, the NSA is celebrating 25 years of providing support and empowerment for people who stutter, their families, and their clinicians.

As a member of the Steering Committee for DIV-4 for Fluency Disorders for eight years (three of which have been spent as Division Coordinator), the chair of the Speech & Hearing Science department at the University of Maryland, a researcher and clinician in fluency disorders and language, and a board-recognized fluency specialist and mentor, I have had a unique opportunity to observe the many contributions the NSA has made in the field of fluency disorders. I can say without hesitation that the NSA is an organization that is worthy of recognition with the Distinguished Service Award, and that now is

the right time to recognize the NSA's many contributions to our field.

In preparing the nomination, I worked closely with two colleagues who serve on the NSA Board of Directors: J. Scott Yaruss, PhD, CCC-SLP (University of Pittsburgh and Children's Hospital of Pittsburgh), and Nina Reardon, M.S., CCC-SLP (LaSalle County Schools, IL). Together, we solicited input from stuttering specialists, clinicians, researchers, NSA members, and families of people who stutter. The respondents' enthusiasm and appreciation for the NSA's many contributions – both for people who stutter and for the profession – was overwhelming. It is clear that people from across our field respect the NSA tremendously and find the organization to be a most valuable resource.

Throughout this document, I have included quotations and comments from the people who provided their input so the awards committee can see firsthand just how critical the NSA has become to our field, in the past, for the present,

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# From the Executive Director:

*Many people collaborated to make this a success*

Through my experience as Executive Director of the National Stuttering Association, my self-perception of my stuttering and what others think about my stuttering has changed dramatically. This was the topic of the recent workshop I did at the British Stammering Association annual conference in London September 7th. I was asked to give a workshop and jumped at the chance to visit Europe and see old friends as well as make new acquaintances.

Preparing for this caused me to take some time to reflect on my personal journey as ED of the NSA as well as how this experience has shaped and formed my self perception regarding both my personal and professional life. This includes my stuttering. Did I want to go to Europe? Yes, of course! Did I want to give the workshop? No way. I can stand before 500 plus of you at our annual conference speaking with ease. Why? Because I am speaking to you. We are one as we come together each year. I have no fears in front of you. But I had a different reaction in thinking about a workshop for a non-NSA audience. My fear began to hold me back in my preparation as I sat at night in front of my computer trying to put it together.

I have only given one workshop in all these years. I have one ready to go...but have been afraid to actually try it out. I know...silly, silly me...but this is my truth. So one night...only four weeks away from departing for my European adventure, I still had nothing on my computer screen and I contemplated ways to cancel.

They had already changed my time once and even then I said...hey, if you need the time...I really don't need to do this. They didn't buy it...so I called my mentor and friend John Harrison, and we talked for hours. He tossed some ideas my way based on all I have shared with him

about my stuttering journey, and he said, "Go sit with it. If nothing comes...then yes, you can cancel. But give it a chance." By the end of that night it began to come together.

Did I do it? Yes! Did people come? Yes! I had standing room only and they sat on the floor! I kept thinking they would realize they were in the wrong room and would get up and leave, so I joked that the door lock was jammed and they couldn't leave. It turned out to be a wonderful experience and leads me again to say to my three favorite words..."because I stutter."

For years "because I stutter" was associated with negatives. I can't do this...because I stutter. I didn't get that ...because I stutter, and this happened...because I stutter. Through years of positive self-talk and a lot of work, these three words have taken on a new meaning for me.

Have you begun this transformation for yourself? You can begin now. Right now.

Success or changing the way we think and believe is not measured by how much we do, but rather, just by the fact that we are doing! Everything we do, every action we ever take is affected by how much responsibility we take for our self. We can wait and let the world take responsibility for us, or we can find a way to take the world on ourselves.

When I began to change my self concept, I learned I had the freedom to choose how I felt about me, my stuttering, my life! You can, too!

When my personal self-concept changed, everything changed. I found I did more, I talked more, I even stuttered more. This happened because I was talking more, expressing myself more and in fact participating in life more!

Just doing...picking up that phone...raising my hand...this is doing my best. I learned it was okay to stutter. When the desire to not stut-



ter because of what others thought lessened, I had the choice as to how I reacted and how much talking I wanted to do. I could actually make a decision to talk or not talk without basing it on my stuttering.

This was an amazing revelation!

So often I hear..."only if"...if I didn't"...and "I wish I could." By managing our thoughts we manage our minds and by managing our minds, we give ourselves the freedom to choose what we think and believe about ourselves. When we realize we have the freedom to choose, we realize we have the freedom to change.

Baby steps. I strongly believe in baby steps. Simply noticing what you are doing instead of concentrating on what you are not doing...or wish you were doing is a big step. In time, the negative feelings and emotions associated with "not doing" can and will be replaced by all that you will notice yourself doing.

Answering that phone, asking for that direction instead of driving around, asking that question...they all will be replaced with the self-realization that you have amazing strength and courage and an incredible will to try again.

You will gain these realizations...all because you stutter.

**Annie Bradberry**  
Executive Director

## Call for Nominations for the 2003 Malcolm Fraser Award

THE STUTTERING FOUNDATION OF AMERICA AND THE SPECIAL INTEREST DIVISION FOR FLUENCY AND FLUENCY DISORDERS ANNOUNCE A CALL FOR NOMINATIONS FOR THE 2003 MALCOLM FRASER AWARD, an award bestowed on an individual in recognition of excellence in the field of stuttering. The award, consisting of a plaque and a \$2,000 award from the Stuttering Foundation of America, will be presented at the 2003 Annual Leadership Conference of the American Speech-Language-Hearing Association's Division 4.

Among other criteria for eligibility, nominees should have highly respected, distinguished ca-

reers in speech-language pathology with specific and multiple contributions that have made significant positive impact on children and/or adults who stutter.

Contributions may be in the areas of 1) clinical services, 2) research, and/or 3) professional training of clinicians.

To request nomination guidelines, please write to: Vivian Sisskin, Division 4 Awards Committee Chair, c/o ASHA, 10801 Rockville Pike, Rockville, MD, 20852. Completed nomination packets must be received at the same address of ASHA by February 15, 2003.



• CENTRAL ARIZONA CHAPTER MEMBERS WHO ATTENDED ANAHEIM WERE (l to r) BRIT KOHLS, TAMMY BETTINGER, LYNN BEJNAR, CATHIE LABARBERA, AND NAKOBEE JOHNSON.

# speaking out

comments and letters

## OFF TO THE PEACE CORP.

I wanted to get the word out that Woody [Starkweather] and I have been accepted into the Peace Corps and seem to be heading for Asia sometime in the spring. We have our Philadelphia house on the market and plan to live in our Chincoteague, VA home until we leave. Then, rent that house while we are gone as it's in such a great tourist area. [If any of you want a great deal on a vacation log house at the beach, let me know. I'll put you on the "insiders list." ]

We have both stopped our private practices, and we have shut down the Birch Tree Foundation, although the web site will stay up a bit longer. These have been hard decisions to make, but once made I feel quite content with them.

Tonight we had our last dinner with our international students who have lived with us this year. As many of you know, here at Penn we've hosted international students learning English these past three years. I think it is from this experience that Woody discovered he loves to teach the English language. That was a precursor to the Peace Corps decision last June. It looks like I will be teaching either Environmental Education or English.

I think we will have e-mail access where we go, and if so and you'd like to be included in my "every-now-and-again" post of life in the hinterlands, do let me know. The Peace Corps is a 27 month commitment, and they do encourage visits from family and friends! So save your pennies. We'll find out more specifics of where and what as the months ahead progress. I think they handle it this way to test our capacity for frustration and our sense of humor.

I have certainly loved my life here in Philadelphia. I still have many resources here I don't intend to give up quickly so there may still be time to get together. After the next three weeks or so, you can write us at 5112 Richardson St., Chincoteague, VA 23336 Our e-mails remain the same for now.

...Janet Givens

## IT'S A NEW WORLD!

This past June I attended my second NSA conference. I also went to the Boston conference last year. After all the excitement of going to Anaheim and meeting more great people, I just need to share my feelings.

I'm 47 years old and the last two years have changed my life completely. For the better, of course. I attended The American Institute for Stuttering's total immersion fluency training with Catherine Montgomery in Manhattan, and I've also been a member of the NSA. Since then I've been a free person.

When I say free, I mean freedom of emotional pain that I lived with all my life. I was ashamed and felt so alone. I stuttered so severely, especially when I was younger. My school days were horrible, and I couldn't even say my own name.

I couldn't wait to be out of school. I never went on to college until two years ago. Since then, I realized I would love to be an SLP specializing in stuttering and love getting an education. I deserve it.

One of my favorite things I do when I enter into a new class is advertise that I'm a stutterer. I can't believe I'd ever do that because of my old embarrassments. I would never have brought up stuttering. It was just the way it was. Funny, I used to think to myself that maybe no one will notice. I didn't accept myself with my stuttering. I was in denial, and I had no control of my voice, or had no idea of what to do. I just struggled. I was in pain.

Since I learned tools and how to use them, and being with so many PWS, and leading support groups, I've learned to accept myself as a stutterer. It's a great feeling. The NSA and all PWS are so important to me. I know what I need, and I need other stutterers in my life. I never want to miss an NSA conference. I get so much out of being there, making new friends and being with the old ones. I am in my comfort zone there with everyone and having good fun, and we learn new things all the time.

Another favorite of mine is the open microphone sessions. Usually I get emotional hearing others speak about their struggles with fluency, and it always brings me back to where I need to be. What great healing that is from all my past hurts and pain. I love being a stutterer, because it's who I really am. I'm proud to be me, and that will never change.

I want to thank everyone at the NSA for all the fun and work they do. Also, I want to thank my wife, Lynne, for all her loving support and encouragement and my children for their love and understanding.

I never have to feel alone again, and I'm so blessed to have so much to offer others. I'm committed to always taking care of myself and do whatever is necessary to have self-respect and good health. That's what we really deserve.

...Bob Koste

## DON'T YA JUST LOVE THE WEB?

Hello, everyone! Our love story has been published as one of the articles in the 2002 International Online Stuttering Conference - my account of how Liv and I met each other through a stuttering website and then fell in love.

To see this article, copy and paste the following link into your website browser: <<http://www.mnsu.edu/comdis/isad5/isadcon5.html>>. When you reach the website, scroll down to "Panel Discussions," then to the last item in this series, "Love Makes the World Go 'Round: Spouses Meeting on the Internet." You might also be interested in some of the other fine articles at this site. Regards to everyone.

... Liv and Piano Player Paul



• PAUL AND LIV IN COLOGNE, GERMANY ON AUGUST 2 NEAR THE END OF THEIR TRAIN TRAVELS THROUGH EUROPE LAST SUMMER.

## HI, MY NAME IS NATHAN PRESSLEY

I would just like to say that I had a wonderful time at the convention. All the workshops that I attended were well put together. I saw some of my old friends and I made a lot of new ones. I had a great time in California. Everything at the convention was good. I hope to see you all next year in Nashville.



• NATHAN PRESLEY WITH ADRIAN PETERSON AND HIS BROTHER LEO PRESLEY ENJOY THE CONVENTION.

## NEW CONTINUING EDUCATION PROGRAM

On November 1st, the NSA launched its new Continuing Education Program in New York City. Over 100 speech-language pathologists and 28 speech pathology students came to hear Scott Yaruss, Ph.D., present "Practical Treatment Strategies for School-age Children Who Stutter." The NSA's Continuing Education Program is our commitment to providing experiences.

In 2003 the NSA has more than 12 one-day programs planned throughout the U.S. to help provide school clinicians, private practitioners, and educators with opportunities to better support children who stutter in developing effective communications and enhance academic and social skills. Our thanks go to Scott Yaruss and other speech-language pathologists who are making this program possible.

# What's Happening?

the latest news • hot items • who's doing what • who went where • upcoming events • etc.

On May 15th, the highest literary accolades were awarded to PWS and NSA member



**Benson Bobrick.** Benson received the "Literary Award" of the American Academy of Arts and Letters at their annual ceremonial in New York. Few (if any) honors can exceed the commendation of one's peers. The award committee (a distinguished one) was made up of Hortense Calisher, Russell Banks, Horton Foote, Ann Beattie, and Galway Kinnell. The award was given in honor of Benson's work as a whole, which the Academy commended for "richness of talent," and for "recreating the past with vividness and power." Benson earned his doctorate in English and Comparative Literature from Columbia University, and is the author of seven books, including *Knotted Tongues: Stuttering in History and the Quest for a Cure*; *The Story of the English Bible and the Revolution It Inspired*; *The Life and Reign of Ivan the Terrible*; and *Labyrinths of Iron: Subways in History*. His works, reflecting a wide-ranging intellect, have been translated into German, Spanish, Italian, Russian, Dutch, Chinese, and Japanese. His most recent book (on the Civil War) will be published next year. Three cheers, Benson! That was quite an honor.

During the week of August 5th, **Elaine Saitta** and **Janessa Thornton**, a friend from graduate school, drove from Seattle to Reno for a little getaway. Along the way, they stopped off in Portland to meet up with fellow NSA member **Pete Hrdlicka**, and over breakfast, Elaine and Pete exchanged ideas on how to help the Portland chapter build its membership.

Elaine also stopped in San Francisco and had dinner with chapter leader **Nora O'Connor** and **Robin Ottesen** who were on their way back from their group's weekend camping trip.

At the end of August, **John and Doris Harrison** flew to the U.K. for 2½ weeks of sightseeing and speaking. John was invited to

give the keynote at the British Stammering Association's annual conference in London. The Harrisons began in London, then headed west to Wales where they visited **Alan and Babs Badmington** and **Gina Waggott** in Abergavenny. John then ran a workshop in Hereford for graduates of the McGuire Program. Back in London, John ran a mid-week workshop for speech therapists. Finally, at the BSA conference, John participated on a panel, ran yet another workshop, and presented his keynote to an audience of 200. You can read John's keynote, entitled "How I Recovered from Stuttering" on the Stuttering Home Page at <http://www.mnsu.edu/comdis/kuster/Infostuttering/Harrison/john.htm>.

The San Francisco chapter hosted their first annual camping trip at Mt. Diablo State Park over the weekend of August 10-11th. People who stutter, family, and friends from the Sacramento, San Francisco and San Jose chapters enjoyed a fun-filled weekend of talking, bonding, board games, food, hiking...and lots of bugs! Everyone pitched in to make a delicious dinner orchestrated by **Robin Ottesen**. **Peter Kao** from San Jose ran the BBQ while **Clark Kelso**, Kari's husband, worked his Coleman Grill like a master chef. **Andrew Schmeling** and his wife **Julie** from San Francisco added their fabulous sense of humor and dry wit! On Sunday morning, San Franciscan **Dakota Brown** cooked a great breakfast, and she got on so well with everyone that she intends on participating in all future local NSA social activities! Nora O'Connor plans to make the camping trip an annual event. Anyone interested in participating in the Northern CA NSA chapter meetings and social out-

ings please contact Nora at [nora95@juno.com](mailto:nora95@juno.com).

The **San Diego and Orange County chapters** got together on August 31st for an outing at San Clemente Beach. This was their first joint venture and a total of 11 members joined in on the fun. They are planning another get together for the holidays.

On September 12th, five members of the **Madison chapter** spoke to a graduate class of SLP's at the University of Wisconsin. After NSA members talked about their stuttering and therapy history, each student asked a previously-prepared question, which gave panel members a further opportunity to expand on how their stuttering affects their lives. The question and answer session gave the students good insights on how people who stutter manage their speech.

On September 20th, CNN interviewed **Nicholas Brendon**, who is best known for his role as Xander on *Buffy the Vampire Slayer*. There were many references to his stuttering problem which almost thwarted the actor's rise to stardom. The article can be viewed on the Internet at [www.cnn.com/2002/HEALTH/09/19/hln.bio.stuttering/index.html](http://www.cnn.com/2002/HEALTH/09/19/hln.bio.stuttering/index.html).

The Philadelphia chapter had **Dr. Joseph A. Stigora** of the Baxter Speech and Fluency Center, Inc. in nearby Chadds Ford, PA, as a guest speaker at its October 3rd meeting. The Baxter Speech and Fluency Center is one of the nine providers in the U.S. of the Janus SpeechEasy DAF/FAF Device that was recently featured on "Good Morning America." Dr. Stigora informs us that there will be a segment on the SpeechEasy device airing on "NBC Nightly News" with Tom Brokaw in the near future.

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• SOME OF THE CAMPERS FROM THE SAN FRANCISCO, SACRAMENTO AND SAN JOSE CHAPTERS.

**WHAT'S HAPPENING continued**

During her two-week vacation, Executive Director **Annie Bradberry** attended the British Stammering Association (BSA) Annual Conference on September 7th and 8th, where she gave a workshop entitled "Five Categories of Change that Can Transform Your Life," based on Annie's perception of her own stuttering and her experience as Executive Director of the NSA and how she has changed over the years. Her workshop, which played to a standing room audience, focused on developing self worth and the rewards of self-discovery.

After the BSA conference, Annie made her way to Bergen, Norway, where she attended the Nordic Conference for People Who Stutter. There she met up with old friends and expanded her worldwide network of contacts in the stuttering community. Some of the people she saw on her trip were **Hermann Christmann** from Denmark, **Edwin Farr** from the UK, **Anita Blom** from Sweden, **Benedikt Benediktsson** from Iceland, and **Bob Rothman, Christine**



• CHRISTINE SIMPSON AND HUSBAND TOBE RICHARDS.

**Simpson** and husband **Tobe Richards**. Annie continues to marvel at what grand experiences she's having...all because she stutters.



• ANNIE BRADBERRY IN NORWAY WITH HERMANN CHRISTMANN FROM DENMARK.



• SOME OF THE THOSE WHO ATTENDED THE NORDIC CONFERENCE FOR PEOPLE WHO STUTTER IN BERGEN, NORWAY: (l to r) BENEDIKT BENEDIKTSSON (ICELAND), ANITA BLOM (SWEDEN), CHERYL VOSS (FROM CHICAGO: ANNIE'S CHILDHOOD FRIEND AND TRAVELING COMPANION), ANNIE BRADBERRY AND EDWIN FARR (UK).



• BIG NEWS!!! NSA OFFICE MANAGER TAMMY FLORES HAS ANNOUNCED THAT SHE'S ENGAGED! SHE AND HER BOYFRIEND, RICH, FLEW TO HAWAII FOR A MUCH DESERVED ONE WEEK HOLIDAY, AND RICH (MANY OF YOU MET HIM THIS YEAR AT THE CONFERENCE) SURPRISED HER WITH A BEAUTIFUL RING. NO DATE IS SET YET...BUT MORE INFO WILL FOLLOW. CONGRATULATIONS, TAMMY!!!



• EACH YEAR THE MINNEAPOLIS CHAPTER GETS TOGETHER FOR AN OUTING AT JUDY JOHNSON'S CABIN. THIS YEAR'S EVENT WAS FILLED WITH LAUGHTER, SWIMMING, CONVERSATION AND GREAT FOOD. ATTENDEES INCLUDED: Back Row: MONA TOFT, RAYMOND BOWERSOX, ALFRED KAYE. Front Row: JUDY JOHNSON, ERIK ZABEL, CAROLYN SAMPSON, FRAN ANKEL.

**A STORY FROM AFRICA continued**

of the burnt outer layer of a colanut seed.

One of the methods I went through in an attempt to cure my stutter was offering traditional sacrifices to the gods as it was believed that stuttering in our family was a curse from the gods to my grandmother who violated the laws of the land. And that was why stuttering was running in our family.

All these cures yielded no positive results and my stutter stood as an obstacle and a terrible monster in my social, academic and economic progress. My stutter held me down from doing many things I would have loved to do – speaking being one of them – and consequently, this affected my interaction with friends and others I had met in my life.

My primary school years were very difficult and troublesome. I grew up in an environment that was socially insensitive to the plight of the handicapped, a society where people were not taught to accept and respect those born with certain handicaps, stuttering being one of them. A society where stuttering like any handicap is taken as a laughing matter.

In my primary school days I was given all kinds of nicknames by my schools mates and even at times by the teachers themselves. I was often an object of ridicule, bullying and teasing.

I remember how I used to fight or weep when I was called by one of my nicknames – choh. In our dialect, *choh* means large tongue. This name arose from the fact that one of our teachers ignorantly associated my stuttering with the fact that I had an extraordinary large tongue which did not move well inside my mouth, and therefore, I stuttered when trying to talk.

My secondary and high school years were no different. The bullying and teasing continued. I still remember one incidence that took place in my history lessons several years ago as if the incident had happened yesterday. On one of my worst days when my stutter was at its peak, I was asked by the teacher to answer a question. I stuttered very severely in trying to pronounce the words "holy alliance." The whole class stared at me with mixed feelings.

When the teacher started laughing, all the students joined him. After the class, they started calling me "Holy Alliance," known for short as HA. Some of my classmates even today still call me HA.

All this humiliation and bad feelings are things of the past. Since I started associating myself with my stuttering friends both in and out of Cameroon, I have witnessed a total revolution in my thoughts about my stuttering. I have

learned a lot on this topic, and this knowledge has really helped me.

The greatest thing I have learned is that my stutter cannot and should not hold me down from doing the things I love to do. I can talk, or better still, stutter everywhere, and my stutter cannot hold me down from talking when and where I wish to.

I can proudly stand up and read in our church, talk in social gatherings where I am invited, a thing I could not do in the past. I have learned that many people are often interested in what I say and not the stuttering manner in which I say it.

This knowledge and behaviour is what I also try to share with my colleagues in the Speak Clear Association of Cameroon (SCAC), a self help movement for stuttering persons in Cameroon whose activities I coordinate.

You readers who still consider that your stutter can stop you from doing many things should get up and no longer use your stutter as your pillow on which to sleep.

... JOE LUKONG TARDZENYUY IS COORDINATOR GENERAL OF SCAC AND A MEMBER OF THE INTERNATIONAL FLUENCY ASSOCIATION. HIS ADDRESS IS P.O. BOX 9598 DOUALA, CAMEROON, AFRICA. HIS EMAIL IS <LUJOTAR@YAHOO.COM>. THE SCAC WEBSITE IS <WWW.STUTTERISA.ORG/CAMEROON.>

# OUR VOICE

NSA young people and parents speak out



## Jackson Montalbano

*An inspiration to us all*

BY CATHY OLISH

*SHORTLY AFTER THE CONFERENCE, I SENT A NOTE TO TWO DIFFERENT LISTSERVES FOR PEOPLE WHO STUTTER, ASKING WHICH PEOPLE INSPIRED THEM THE MOST FROM THIS YEAR'S CONFERENCE AND WHY.* The majority of the responses I received indicated Jackson Montalbano as being their inspiration because of his courage and strength to speak in front of hundreds of people at this year's closing ceremony. We were all so proud of Jackson and I hope he has inspired others to have the courage to do what he did that day — say what he wanted to say regardless of how his words came out or how long it took him to say what he wanted to say. What he did and said while at that podium will not soon be forgotten.

Here's Jackson's story.

He was born on May 5, 1994, in a suburb in Illinois. Jackson's parents, John and Chris, first realized that he had speech difficulties at age three, but did not associate it with stuttering at that time. One year later, Jackson started therapy to help him manage his speech.

After three years of therapy with the school's speech therapist, Jackson and his family were introduced to SLP Nina Reardon who was finally able to put a name to his difficulties — stuttering. On that day, Jackson's mother decided that everything she had tried to do to improve his situation had not worked. Now she was going to let Jackson steer his own boat. From this point on, he made all the decisions regarding his speech, his therapy sessions and even the tools he learned and when to use them.

There is not a support group for kids who stutter in Jackson's area, but he sometimes has contact with other kids who stutter by participating in speech therapy groups which he thinks are a lot of fun. Aspects of therapy that have helped Jackson better manage his stuttering, which is moderate, have been cancellations, easy onsets, slide outs and block outs. Jackson enjoys going to speech therapy, except for the long drives.

Anaheim was Jackson's first conference, and one both he and everyone who attended will not soon forget. When Nina first mentioned the



conference back in March of this year, Jackson really wanted to go as he thought it would be very cool and a lot of fun. He arrived in Anaheim with his mother and sister Nicole with no idea of what was in store for them, except for a trip to Disneyland and the baseball game on Friday night.

The people they met were "amazing" and the workshops felt as if they had been tailored just for them. Jackson was surprised that there were so many children who stuttered. Teenagers and adults, too. He had thought only children stuttered. Jackson was incredibly comfortable the entire time he was at the conference.

When Nina asked Jackson to speak at the closing ceremony, he felt uneasy and apprehensive. He knew there would be lots of people watching and listening to him speak, but after much thought, he decided he was up for the challenge. When he was up at the podium looking at everyone waiting for him to speak, he was very nervous. He tensed up and then just started to talk.

What Jackson said while high up on the podium was part planned and part spontaneous. He was the highlight of the closing ceremony

and he taught his audience to not be afraid to do things or say things because you stutter. We should all follow in his footsteps.

Jackson is the only one he knows in his school that stutters and his friends always ask him about it. He tells them that he was born this way and he stutters, and they say "cool!" His friends have been very accepting of his stutter. Although Jackson is nervous when speaking in front of groups, such as in school, he doesn't let his fear stop him. He just does it. He has never spoken in front of his class about his stuttering but is thinking about doing that this year as he starts the third grade.

The one thing Jackson learned from his first conference was that it is okay to stutter. He remembers everything he learned and experienced at the workshops and sessions he attended. One of his favorite memories of the conference was hanging out with the teenagers. He seemed to really enjoy them the most — just talking to them was a lot of fun. The scavenger hunt was also very memorable.

Among the friends he remembers meeting is a boy named Will. He was funny and nice, and Jackson says it is nice to have a friend like him.

When asked what the word "stutter" means to him, Jackson replied, "It means that I get tense in my vocal cords." He said if he could draw a picture of the word stutter, he would draw something like a ghost that is always flying around him.

Jackson likes to play all kinds of sports, but baseball is his favorite. His dad coached his little league team this year. Jackson also likes to read the sports section of the newspaper and collects baseball cards. He enjoys watching funny movies and his favorite movie is "Like Mike." He also has a pet dog named Max.

Jackson wants to be a pro baseball player when he grows up. Watch out New York Yankees! Jackson is not going to let his stuttering stop him from doing what he wants to do, and neither should any of you!



and well into the future.

Specifically, I will demonstrate how the NSA has played a key role in:

- (a) **advocating for consumers**, including people who stutter, their families, and the clinicians who work with them;
- (b) **increasing public awareness** about stuttering and correcting common misconceptions about people who stutter;
- (c) **improving educational opportunities** for speech-language pathologists (SLPs) and students through publications, CE programs, and collaborations with university training programs;
- (d) **supporting research on stuttering** by fostering collaborations between scientists and consumers; and
- (e) **providing service to ASHA** and its members.

The breadth of these contributions is truly remarkable, and the value of the NSA for ASHA and people who stutter alike cannot, in my opinion, be underestimated.

#### CONSUMER ADVOCACY AND SUPPORT

The NSA's mission is to bring hope, dignity, support, education and empowerment to children and adults who stutter. The organization fulfills this mission – and much more – every day. Support for people who stutter is provided through several of the NSA's key programs, including: *local chapters*, the *annual conference*, *youth days* and *adult workshops*, and numerous *publications*.

**Local Chapters.** The NSA began in 1977 with a single group of people who shared the common bond of dealing with stuttering. Since that time, the NSA has grown to include more than 3500 members in 80 local chapters covering all 50 states. Weekly or monthly local chapter meetings provide the opportunity for people to come together with others who have faced the same challenges, in an atmosphere of complete acceptance and understanding. For many people who stutter, the local meeting provides the first real opportunity to speak freely.

Members who attend NSA meetings gain support by hearing about other people's experiences, and they provide support by helping others with their own journey. Participants gain self-acceptance, confidence, and trust, and these experiences help them improve their lives. Here is just one example of a member's feelings about the local chapter program. Marilee Finni, M.A., CCC-SLP, wrote:

*Through the NSA, I have had role models that have changed my life. About a month ago, I was very anxious about a presentation that I was giving in a high school about stuttering. I was anxious because I had been teased the last time I went to this school. Before the presentation, I contacted [a member] via e-mail. He took the time to give me the most encouraging words you could imagine. My Cleveland chapter gave me many words of encouragement when I was feeling like I wanted to give up.*

*While giving the presentation, I felt an extreme amount of freedom. I felt free to be who I was. In feeling this, I was empowered and was able to be an effective speaker despite my stuttering. The NSA has helped me to come in contact with my true self and in doing this, I have discovered a rich life like I often dreamed of.*

*Thank you NSA for giving me the opportunity to understand that I am so much more than my stuttering and for providing me with role models that have gone before and have done great things despite stuttering.*

**Annual Conference.** The NSA hosts an annual conference that brings together hundreds of people who stutter from around the country. This year marks the 19th annual conference, and the expected attendance is more than 600 people who stutter, family members, and professionals.



For many, the annual conference is the highlight of the year. For people who know the isolation that can result from a lifetime of stuttering, there can be no parallel to the experience of finally being able to express themselves freely and fully. Attendees find themselves surrounded by people who accept them for who they are, not who they have to pretend to be.

Walter H. Manning, PhD, CCC-SLP, Professor and Associate Dean, School of Audiology and Speech-Language Pathology, University of Memphis wrote:

*I attended my first national annual meeting in 1989. I quickly saw the power of the support that was available to the attendees, mostly people who stuttered, to be sure, but also spouses, parents, the brothers and sisters of those who stuttered. It was clear that these people had a passion for their mission. Their mission was one of overwhelming and inclusive support for everyone who attended. I saw the power of this support, how it elevated and encouraged those who took part, and how it carried over in the weeks and months following this annual gathering. I saw how the NSA meets an essential need for people doing their best to survive in the culture of stuttering...*

Unless you have been a witness to the impact that the NSA has on its members, it can be somewhat difficult to explain. For years I've told audiences that everyone who is really interested in helping those who stutter should attend at least one annual meeting of the NSA.

Perhaps the best way to explain that impact is to tell a story from the 1989 NSA meeting that I attended. It was near the end of the conference and the session was called "Open Mic." The idea was that anyone in the large room of

nearly 300 people could walk up to the microphone and say whatever they wanted. Most would simply say their name and where they were from – a formidable task for anyone who had never spoken in front of more than a few people. A daunting and magnificent challenge for someone who had stuttered for decades.

Each person who was able to gather the courage would walk down the aisle to the microphone and take their turn. Some were reasonably fluent and spoke with relative ease. Others struggled and stuttered, sometimes dramatically, but took part. In each case everyone was completely accepted, and the audience would applaud for the participant.

Near the end of the one-hour session a young woman slowly walked down the aisle and approached the microphone. The crowd quieted as she began to say her name. She began with the first syllable, and it was obvious that she was stuck. She tried again. And again, this time getting through the second syllable but not the final one. And still she would not give up. The room became completely silent in anticipation of the last syllable of her name. But the sound was not there.

Finally she looked down, defeated. She slowly began to turn to walk back to her seat. At that moment someone in the crowd whispered "Go ahead." Others quickly took up the chant and in a few moments the entire audience was saying together over and over "Go ahead." She looked up, turned back to the microphone, tried again and said "My name is Barbara." There was not an eye without a tear in that large room when everyone spontaneously stood up and gave her a standing ovation.

The NSA's Annual Conference also has a separate program just for youth and families. Mary Ellen Kremer, parent of two teenage boys who stutter wrote:

*As parents, it is just so hard to see our children suffer. Two of my three boys stutter. What a feeling of desperation and sadness I felt. I certainly was not much support for either one of them, I'm sure. I tried to help, but I really didn't know how to. We arrived at our first conference very scared—feeling lonely and isolated. But I sure didn't feel that way for long.*

*We soon found so much love and acceptance from the NSA members we had just met that we were able to spill our hearts and souls out about our experiences. That's when the healing began.*

*WOW! We weren't the only ones like this after all. At each conference, I listened and consoled and cried with a lot of the new moms and dads, and I think with each new encounter, I began to feel the load lifting off my shoulders. By helping others, your heart begins to heal. So now, instead of trying to fix each situation for my son, I let him know that the NSA is there for him.*

After every annual conference, the NSA newsletter is filled with similar stories about how

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**ASHA'S DISTINGUISHED SERVICE AWARD** *continued*

the NSA touches the lives of all who attend. Members talk about how they want to keep their feelings of confidence, acceptance, and empowerment alive and with them throughout the year. What makes this truly remarkable is the fact that these feelings can be so rare for people who stutter. It is through the NSA that conference participants finally find this connection that dramatically and tangibly improves their lives.

**Youth Days and Adult Workshops.** During its 25-year history, the NSA has directly touched the lives of countless children and adults who stutter through more than 200 youth day programs and more than 500 adult workshops. These amazing events bring people who stutter together – often for the first time – to experience the love, healing, and support found in the NSA.



The importance of providing support to children at a young age cannot be underestimated. Now that the organization has been in existence for 25 years, there are members who have “grown up” in the NSA. They received support as children that helped prevent the development of negative feelings and emotions that so often characterize stuttering. Today, they can continue that legacy by providing support to the next generation of children who stutter.

It is clear that this is only the beginning for this organization, and as the NSA expands, this cycle of life-long members supporting and nurturing younger children who stutter will continue and further enhance the impact of this unique organization.

Debbie Nicolai, NSA parent, wrote:

*The NSA offered a Children's Workshop near our home, and my daughter and I went with the intention of learning little and leaving early. We ended up staying for the entire day and learning so much more than we anticipated.*

*My daughter had never met anyone who stuttered before and she was surprised and relieved to finally meet other people who stuttered. Because she now felt that she was not alone, she gained a new confidence of herself and her speech.*

*As we were waiting to attend the national conference, she decided that she needed to talk about her stuttering to the students in her classes. She wrote a speech about her feelings while stuttering, what a listener can do to help a person who stutters, and some of the facts of stuttering. This class of eleven-*

*year-olds listened to my daughter with all of the bumps and repetitions of stuttering and applauded her as she finished. There were a few tears and a lot of new respect for my daughter.*

*I feel that this speech was made possible because of the NSA. She sent a copy of her speech to the NSA, and it was printed in the NSA monthly newsletter. This article prompted many supportive emails from people of all ages around the world sharing their experiences and offering their congratulations. My daughter's confidence and acceptance level of her stuttering has soared in the past two years. I feel these changes are largely due to the NSA.*

Another example, from Julie and Mark Whittaker, NSA parents:

*Just want to say a BIG THANK YOU for the wonderful workshop in Tacoma. The NSA speaker [a certified stuttering specialist and NSA board member] was so knowledgeable and kind. I was in tears almost the whole day. Not tears of despair but tears of hope. Hope that my daughter will be ok with who she is and that she stutters. Hope that she will not live in fear of being teased but that she will have confidence to face her fears. Hope that she will know she is not alone.*

*Annie Bradberry [NSA Executive Director], you are a great role model for my daughter. I have to let you know that after the conference my daughter was teased at school by a girl who has teased her quite often and has really upset her in the past. This time she called my daughter the Stutter Girl and my daughter told her, "So what! It's just a part of who I am and a part of life" !!!! She feels so good about herself. Thank you, for I know the NSA workshops have helped her so much.*

The children express their gratitude to the NSA as well. After a recent youth day, a child wrote:

*My family and I went to the stuttering youth day. I really enjoyed it because I was with other kids who stuttered, like myself. Me and my parents will be coming to the annual conference this summer! I would like to let other kids who stutter know that they should try a workshop out. The kids there stutter, and are interesting to be with. I feel opened up when we are all together.*

Stories like this are repeated over and over again, demonstrating the power of the NSA for helping children and adults learn to cope with their stuttering and get the most out of their lives.

**PUBLICATIONS.**

The NSA also supports people who stutter through newsletters, including:

**Letting GO.** A monthly newsletter, with a distribution of nearly 5,000 people who stutter and their families, clinicians and researchers in stuttering, and others. *Letting GO* includes a special section entitled *Our Voice*, written by and

for teenagers who stutter.

**Stutter Buddies.** A quarterly newsletter written by and for children (ages 7 - 12) who stutter.

**CARE: Connections, Advocacy, Resources, and Education.** A quarterly newsletter that helps parents face the challenges of seeking treatment and help for their children who stutter.

The purpose of these newsletters is to help NSA members know that “they are not alone” in facing their stuttering. The newsletters give people who stutter a voice – each issue includes stories about members’ experiences with stuttering, sharing their challenges and successes. Through this, all members have the opportunity to receive and provide support and encouragement.

In addition, the NSA publishes books to help people learn to live with stuttering, including:

**Preschool Children Who Stutter: Information and Support for Parents.** A new booklet that helps parents achieve the best possible outcome for their children through education and support.

**Our Voices:** A collection of stories from our publications for children, teens, parents and the speech-language professional.

**How to Conquer Your Fears of Speaking Before People.** A self-help guide to foster improved communication skills in people who stutter.

**Jeremy and the Hippo: A Boy's Struggle With Stuttering** and **The Adventures of Phil Carrot: The Forest of Discord.** Two children's books written by NSA members that can be used to help school-age children come to terms with their stuttering and learn to communicate more effectively.

The NSA has also developed numerous pamphlets, posters, videotapes, and other resources that help people who stutter feel connected to the broader stuttering community. Many of these publications were developed in concert with ASHA members, thereby demonstrating both the commitment of the NSA to ASHA and the commitment of key ASHA members to the NSA.

The impact of the NSA's outreach through its publications is tremendous. In the past 25 years, the NSA has distributed over 700,000 pieces of literature to parents, clinicians, people who stutter, schools, and hospitals. These efforts have touched thousands of lives. From showing older children, teens, and adults who stutter that they are “not alone” in facing their stuttering, to helping parents of young children who stutter realize that there is hope and that their children can lead successful lives, to providing needed resources for SLPs who are unsure of how to help their clients, the NSA demonstrates its value for consumers and professionals every day.

**PUBLIC AWARENESS**

Stuttering is a poorly understood communication disorder. People who stutter are consistently portrayed in the media as being nervous, inept, or sensitive. Family and parent magazines frequently offer inaccurate advice and inappropriate recommendations about what to do for young children who stutter, and such advice of

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ten leaves parents confused about how to help their children.

The NSA has provided an invaluable service in working to correct these misconceptions and increase the public's understanding and acceptance of stuttering. In the past 25 years, the NSA has distributed over 17,000 public service announcements (PSAs) to newspapers and radio and television stations and has announced countless press releases and media alerts about stuttering.

Another example of the NSA's efforts to increase public awareness of stuttering was the "Year of the Child Who Stutters" workshops conducted nationwide in 1996. Funded by ASHA, these Youth Day events conducted simultaneous in twelve cities in the U.S. and Canada helped children and families learn to live with their stuttering while at the same time creating media awareness of stuttering and the need for improved public education about this disorder.



Similarly, the NSA played a key role in establishing National Stuttering Awareness Week, as highlighted by NSA Co-founder Michael Sugarman:

In May 1988, in response to the advocacy of NSA members and in conjunction with local congressional representatives, the president signed a proclamation declaring the second week in May National Stuttering Awareness Week. The NSA has been continuing to educate the public through news releases and public service announcements during this week in May.

Dick Curlee, PhD, emphasized the importance of these efforts: "Each year, NSA distributes thousands of PSAs to print and radio/TV media, posters and literature about stuttering to clinicians, schools, and hospitals. Such activities have been highly successful in raising the awareness of the public about stuttering and about the rights of persons who stutter."

Larry Molt, PhD, CCC-SLP, Associate Professor, Auburn University, and Associate Coordinator for the the DIV-4 steering committee, added: "NSA's advocacy and public awareness efforts have been exceptional. It has served as a voice to Hollywood and the media, sensitizing writers, producers, directors and reporters to what stuttering really is, and to the dangers of the stereotypical portrayal of stuttering. Because of the NSA's efforts, many films and other media offerings have provided a more accurate portrayal of people who stutter, which is so important for general public understanding of the disorder."

The NSA has worked tirelessly to increase public awareness of stuttering and to correct common misconceptions about people who stutter. These efforts will ultimately lead to a world where people who stutter can experience greater acceptance and understanding.

#### EDUCATION

Numerous surveys have shown that many practicing SLPs are not comfortable with their skills for working with people who stutter. The NSA has worked to improve this situation by providing needed education to SLPs and students alike, through its participation in graduate courses on stuttering, its growing continuing education programs, and publications designed to help SLPs and other professionals understand stuttering and provide better service to people who stutter.

**In-class presentations.** The educational service that has been provided to ASHA members-in-training by the NSA has been immeasurable. In the twenty years that I have been teaching fluency classes, scores of NSA members have come to work with my graduate students. My experiences are far from unique. All of the faculty we contacted regarding this nomination indicated that the local NSA chapter was available to support their own teaching.

I cannot think of another self-help group that is so diligent in its support of students and faculty. Indeed, ASHA found the NSA's in-class presentations to be so valuable that it supported these efforts with a training grant so NSA members would be able to teach more students and clinicians about stuttering in a variety of settings including graduate training programs, schools, and hospitals.

**Continuing Education.** For years, the NSA has partnered with university programs to provide continuing education (CE) programs to clinicians across the country. Many stuttering specialists and faculty in fluency disorders at ASHA-accredited graduate training programs have found this to be particularly important in this time of changing scope of practice and training requirements. The NSA is currently completing the paperwork to become a fully accredited CE provider, and this will provide the opportunity for the organization to greatly expand its CE efforts, thereby providing an even greater educational service to the profession.

**Educational Materials.** The NSA has created numerous brochures and pamphlets to support clinicians, including pamphlets about how children can present information about stuttering in the classroom, how listeners can best interact with and support people who stutter in conversation, and how teachers and others can work with children who stutter to facilitate success in the classroom.

**Educating the Experts.** Finally, a rather surprising way in which the NSA provides education is in educating the experts themselves. For example, Robert W. Quesal, PhD, Professor and Program Coordinator at Western Illinois University and member of the DIV-4 steering committee wrote: "As a professional, I have met many

people who stutter through the NSA, and those people have helped me to broaden my understanding of stuttering. My 'one size does not fit all' philosophy about stuttering has evolved from meeting the many different individuals who stutter in the NSA and from learning about their personal experiences with stuttering."

Dick Curlee, PhD, CCC-SLP, Professor Emeritus, University of Arizona, added: "Its publications and members have contributed in many ways to expanding my understanding of the challenges of stuttering and the range and variety of reactions to such challenges. My teaching and clinical work have been enriched as a result, as has my own personal growth."

Through all of these avenues, the NSA is providing needed education about stuttering that improves the clinical practice of SLPs who work with people who stutter and, ultimately, helps people who stutter lead happier, more productive lives.

#### RESEARCH

The NSA has long supported the research efforts of scientists in our field, whether through surveys of the membership conducted by the NSA leadership or through participation by local chapters and members in research studies.

Most recently, the NSA has greatly expanded its programs for supporting research and facilitating interactions between scientists and people who stutter. In 1998, Dr. Lee Reeves, the NSA's chairman of the board of directors, established an NSA Research Committee (NSARC), a panel comprised of leading researchers in fluency disorders and consumer representatives from the NSA membership. This partnership represents the first systematic collaboration between the professional and consumer communities in the field of stuttering.

The NSARC is charged with conducting research of relevance to the field of stuttering and, importantly, fostering collaboration between scientists and consumers. Since that time, the NSARC has completed two research projects examining the speech therapy and support group experiences of NSA members (to appear in the *Journal of Fluency Disorders*).

The NSARC has also helped 15 independent scientists identify and recruit participants for research projects. Thus, this collaboration has supported researchers seeking to learn more about stuttering and has furthered our understanding of stuttering in a real, tangible way.

This June [2002], the NSA will introduce yet another initiative to facilitate research in fluency disorders when it hosts the first-ever joint symposium for scientists and consumers. This symposium is specifically designed to facilitate collaborations among researchers and to strengthen the relationship between the community of scientists and the community of people who stutter. The reaction to this event from both researchers and consumers has been overwhelmingly positive, with participants recognizing that the outcome of this historic meeting has the poten

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tial to set the agenda for research in stuttering for years to come.

#### SERVICE TO THE ASSOCIATION AND ITS MEMBERS

Perhaps one of the most important areas where the NSA has had a positive impact on the field of fluency disorders is in developing and improving the relationship between people who stutter and the professional community. Nearly everyone we surveyed commented on this. Here are several quotes from the authorities we consulted:

*Stephen B. Hood, PhD., CCC-SLP, Chair, Speech and Hearing Science, Univ. of South Alabama:* — “The NSA has done much to encourage a positive, productive, and purposeful relationship with SLPs who seek to understand, prevent, and treat the problem of stuttering in children and adults.”

*Gary Rentschler, PhD, CCC-SLP, Clinic Coordinator, Speech-Language Pathology, Duquesne University:* — “NSA is taking a leadership role in bridging the gap between research, clinical practice, and consumers by providing a forum for groups to work together. SLPs have purposefully been included in NSA events, meetings, and activities. This has created a forum for dialogue between professionals and consumers.”

*Bill Murphy, MA, CCC-SLP, Purdue University and Member, DIV-4 Steering Committee:* — “I feel the NSA started the whole revolution we now see in stuttering therapy. I could strongly argue that the NSA actually created the energy that led to the formation of DIV-4.”

Many of the respondents highlighted ways that the NSA has been a key supporter of ASHA and its programs.

*Dr. Dick Curlee, chair of the inaugural specialty board for fluency disorders, wrote:* — “The NSA strongly supported ASHA's establishment of DIV-4 and the clinical specialty program in fluency disorders. Members have attended DIV-4 conferences, served on division committees, and Michael Sugarman, one of NSA's co-founders, was elected to the inaugural Specialty Board on Fluency Disorders and served as its treasurer for three years. [The NSA's current Chairman of the Board, Dr. Lee Reeves, now serves in this same position.] Thus, NSA has supported ASHA programs, as well as those members of ASHA with clinical or research interest in stuttering.”

Even more striking were comments about how the NSA has worked to improve the relationship between people who stutter and ASHA and its members. Here are several examples:

*Walter H. Manning, PhD, University of Memphis:* — “When I attended the early meetings, I felt a level of hostility directed toward SLPs for not providing what many felt was adequate help to people who stutter. As an SLP and someone with a history of stuttering, I was sensitive to that hostility. I felt that some of it was justified. Our level of service to those who stutter is still not what it can be. That may be a strange thing to point out in a letter recommending the NSA

for the ASHA Distinguished Service Award; however, it is important to realize that over the past 15 years, that hostility has abated and there is now a dynamic and positive working relationship between the NSA and SLPs. One of the best examples of this “coming together” is seen in the area of specialty recognition. Having been involved in the early stages of Specialty Recognition for Division 4, I have no doubt that the development of the Specialty Board for Fluency Disorders would not have become a reality without the advocacy and support of the NSA.”

*Stephen B. Hood, PhD, University of South Alabama:* — “Largely through the efforts of the NSA, SLPs and consumers have gradually begun to combine resources and work together. Increasingly, SLPs are attending and participating in NSA events; NSA leaders attend and give presentations at ASHA events such as DIV-4 Leadership meetings and the Annual ASHA Convention; and NSA Chapters often have booths at meetings of state speech and hearing associations.”

*Robert W. Quesal, PhD., Western Illinois University:* — “The NSA has taken the leadership role in bringing SLPs and people who stutter together. Rather than fostering the ‘us against them’ mentality that ruled for so many years (and probably hindered progress on many fronts), the NSA has worked very hard to ensure that SLPs and people who stutter – the ‘consumers’ – are working toward the same common goals: to make life better for people who stutter and their families.”

*Lawrence W. Molt, PhD, CCC-SLP, Auburn University:* — “I also see what the NSA has done in service to ASHA. In its early days, there was a somewhat adversarial relationship between NSA and SLPs. Many members turned to NSA because of a history in failing to succeed with conventional speech therapy treatment, and some degree of anger and resentment was often present. The NSA leadership did not dwell on past failures and disappointment. Instead, they welcomed SLPs as NSA members. They saw the value of a pro-active relationship, and it has flourished, much to the benefit of both sides. As a member of both ASHA and of the NSA, I am proud to say that the efforts of the NSA have improved what SLPs have to offer people who stutter, and it has dramatically improved the relationship between professionals and consumers.”

The importance of the NSA's efforts to build ties between consumers and professionals cannot be underestimated, particularly given the concerns that many people who stutter have voiced about their success in traditional treatment programs.

#### IMPORTANCE OF THE ASHA DISTINGUISHED SERVICE AWARD FOR THE NSA

Perhaps the most remarkable aspect of all of these accomplishments is the fact that the NSA is actually a very small nonprofit organization. All of these achievements were completed on a shoestring budget, and with only two regular staff members in the national office. The NSA does

its work through the dedication and commitment of volunteers, from the membership and from the community of SLPs and researchers in fluency disorders. The people behind the NSA are passionate about improving the lives of those who stutter, and they are devoted to their association. Recognition of the impact of the NSA for the profession of speech-language pathology during the NSA's 25th anniversary celebration would mean a tremendous amount to this organization and to the people who have devoted their lives to this worthy cause. Even beyond this goodwill, however, is the tangible benefit for improving and expanding the NSA's outreach programs that would accompany ASHA's formal recognition of the value of the NSA.

#### SUMMARY

In sum, the NSA has made significant contributions to the profession of speech-language pathology at many levels. In reading the comments from children and adults who stutter, parents of children who stutter, SLPs, and researchers, I was struck by just how many lives have been touched by the service of the NSA, on both the professional and personal levels. The following comments summarize the feelings of those who contributed to this nomination:

*Robert W. Quesal, PhD, CCC-SLP, Western Illinois University:* “We are lucky that the NSA has been there to provide help and support for both stutters and SLPs. The NSA is *the* organization at the forefront of research, treatment, and continuing education for stuttering.”

*Lawrence W. Molt, PhD, CCC-SLP, Auburn University:* “As a person who stutters myself, I feel a deep debt of gratitude to the NSA for what it has done for individuals who stutter in its 25 years of its existence. Thousands of lives have been changed for the better because of their efforts. That alone makes the NSA worthy of the ASHA Distinguished Service Award.”

*Gary Rentschler, PhD., CCC-SLP, Duquesne University:* “NSA has been instrumental in raising public awareness of stuttering and connecting with people who stutter who have isolated themselves from others; too many of whom had given up hope. The connection and support is of tremendous benefit toward encouraging people to re-discover themselves. NSA has made significant contributions reaching out to children, adolescents and their families through publications, conferences, workshops and information. NSA has taken self-help, the basic tenant of the organization, and created a structure of empowerment for many who stutter. The inclusive philosophy of NSA has built bridges instead of barriers. Their bridges have transported individuals who stutter, propelled those (students, community members, and the media) interested in learning about stuttering to improved levels of understanding, and provided new perspectives for SLPs working with people who stutter.”

For all these reasons and more, the NSA is worthy of ASHA's Distinguished Service Award, and this year, the NSA's 25th Anniversary, is a fitting time for this important recognition.

# Want to Know How to Throw a Party? Ask Royal Oak. . .

**An entire weekend of fun**

BY BERNIE WEINER

THE ROYAL OAK, MICHIGAN, CHAPTER HELD THEIR SECOND ANNUAL MICHIGANDERS WHO STUTTER PICNIC ON AUGUST 17, and it was just as successful as the first with 26 attending.

We had a fantastic time, beginning with the arrival of our out of town guests from California, Toronto, St. Louis, Cleveland, and New Jersey. The festivities began on Thursday night with a dinner at Bahama Breeze, a Caribbean themed restaurant, with Cari Caldwell, Ed Weiss, Mark DeBiasio, Cathy Olish, Sandra Patino, and myself. Kudos to Cathy Olish for her many trips to the airport and back to make sure that our out of town people saw a friendly face when they got to Michigan.

On Friday, we were joined by Jim Petrowicz, from New Jersey, for a trip to one of our world-class tourist attractions—Greenfield Village and the Henry Ford Museum. And yes, thanks to

Cathy Olish, we spent about an hour riding in a circle on a steam locomotive.

On Friday night, we had 16 people from our chapter and guests at a dinner on a restaurant patio where we were able to watch the classic cars take part in the “Woodward Dream Cruise,” the world’s largest parade of hot rods, muscle cars, and antique cars. It was quite the party atmosphere.

Saturday was the picnic and once again, Jim Abbott and myself were pleasantly surprised at the turnout. The weather was perfect, and we had lots of food. We did the usual picnic things—eating, horseshoes, more eating, water balloon toss, more eating, and a lot of talking (sandwiched in between the eating). We hope to make this picnic/dream cruise weekend an annual tradition. The two events just seemed to go great together.

We capped Saturday night off by going to a house party at the home of Cary Kreiger, an SLP at Beaumont Hospital. Once again, a great opportunity to meet new people and enjoy the summer evening.

We really enjoyed having people from out of town attend. Cari Caldwell, Scott Yeager, Ed Weiss, Jim Petrowicz, Sandra Patino, and Mark DeBiasio made it extra special for us this year. Hopefully, more people from the surrounding states will join us in 2003. Jim Abbott and I envision this picnic as sort of a post-convention get together, to continue the good vibes.

Once again, we all saw the effect of the NSA on people and how friendships just naturally happen, and continue to grow.

... BERNIE WEINER IS CO-LEADER OF THE ROYAL OAK CHAPTER.



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# Chapter News

from Bonnie Weiss

## BOCA RATON, FL

The Boca Raton group met on October 2nd. Nine were present, including two newcomers. Vkiresh Anand led the meeting with a demonstration of the "Speaking Up" exercise from John Harrison's book. This led to discussions of the importance of confidence, how opening up about speech can actually decrease stuttering, and how different therapies have different definitions of success.

## N E W C H A P T E R BOWLING GREEN, OH

Five members were present at the first meeting of the new Bowling Green chapter on October 21st with Rodney Gabel facilitating. Everyone is motivated to make this chapter a very active one and activities for future meetings include inviting graduate students, family members, and significant others to attend. Members are interested in using the group as an opportunity to refocus on therapy activities, learn more about stuttering, and have a chance to interact with other people who stutter. The group also is interested in exploring ways to interact with the community through work with the schools and perhaps interacting with other chapters that are close to them. They are planning on meeting one Sunday afternoon or evening a month from 4 to 6 p.m. in the Department of Communication Disorders at Bowling Green State University.

## N E W C H A P T E R LEHIGH VALLEY, PA NEW CHAPTER

This is a new chapter started by Kathy Rector. The chapter is in northeastern Pennsylvania, in

the Allentown, Bethlehem, Easton area. Their first meeting was on September 25th.

## MANKATO, MN

The Mankato chapter recently viewed a film by a producer in Belgium, Erik Lamens, a person who stutters. Also, a member of the group summarized an article in the book *To Say What Is Ours: The Best of Letting Go*. Judy Kuster and Preston Smith, who attended the convention in Anaheim, passed out questionnaires—one from the Stuttering Foundation of America, and one regarding chapters.

## PHILADELPHIA, PA

At the September 3rd meeting, a fellow Toastmaster of chapter leader Lou Madonna was the guest facilitator. He is a psychotherapist and a coach. Lou says that he had an engaging presentation, asking those present to examine their beliefs, self-talk, and self-esteem with regard to stuttering. She gave some pointers on using yoga and meditation techniques for calming, relaxing, and centering. Thirteen people attended this meeting.

## PITTSBURGH, PA

Alan Reznick has stepped down as chapter leader in Pittsburgh. Dan Kremer and Joel Lurie are the new co-leaders. At the first meeting that Dan and Joel facilitated, they had fun experimenting with the Lombard Effect, the Edinburg Masker, and classical music. Each person in attendance was asked to stand, pick a "Story Starter" on the board, and begin to tell a story. After a few minutes, classical music was started as an accompaniment and they were asked to alter their story with the tempo or mood of the music. Dan reports that everyone told some very good stories.

## UPSTATE SOUTH CAROLINA

This very active chapter planned an open house on Tuesday, October 22nd at the Speech, Hearing and Learning Center in Greenville, SC. Jake Ohlinger and Jimmy Walker were co-chairmen for this. The purpose of the open house was to educate others on stuttering as well as assist with questions from people who know someone who stutters.

## WHY ARE YOU LOOKING AT ME LIKE THAT?

BY ANITA S. BLOM, SWEDEN

This poem is dedicated to an inspirational friend and was read during the Nordic Conference for People who Stutter in Bergen, 13-15 September.

*Why are you looking at me like that?  
Have you never seen me this sad before?  
I love to talk  
Joke and tease  
Tell you what I think and feel  
Answer back  
Explain things  
Tell you how much you mean to me  
Tell you why I'm so sad  
But the words, they just get stuck*

*Why are you looking at me like that?  
Have you never seen me this angry before?  
People talking pass me  
They laugh at me  
They cut me off and fill in my words  
They don't believe in me  
I can, but cannot show it  
Don't get the chance  
And I can't even yell at them  
Because the words, they just get stuck*

*Why are you looking at me like that?  
Have you never seen me this happy before?  
I laugh and I dance  
I chat and I joke  
I don't care  
I have a new friend  
I love my job  
My brother just called  
My daughter was praised in school  
And the words, they just keep on flowing*

*Why are you looking at me like that?  
Have you never seen me this confident before?  
Sure I can talk, if you just give me some time  
Sure I can do the job, if you just let me show it  
Sure I sing you a song, if you just hear me out  
I feel good  
I know I can  
I know I'm ok  
I'm proud of who I am  
And the words? Who cares!*



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