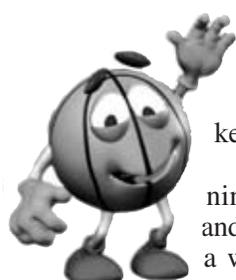




- Nick Brendon Birthday Bash
- World's Largest Tiger Reserve
- Empowered: A Success Story
- From Washington to Kenya
- Golf Tournament Benefits SFA

## New "Kids for Kids" DVD Stars Swish and His Young Friends



Who better than kids to talk to other kids about talking?

Well, maybe a basketball named Swish.

Swish!—it's a winning sound in hoops, and now it's the name of a winning cartoon character created to teach

kids about stuttering.

Swish, an animated basketball with engaging, human-like features, is one of the stars—along with his young human friends—in the Stuttering Foundation's new DVD by kids, about kids, and for kids.

Swish is the creation of students Ali Modara, Helen Kang, Rich Sun, and Michelle Jackson in the Computer Graphics Technology Department at Purdue University, under the direction of Dr. Mark Bannatyne, head of the department. The speech-language pathology team is comprised of Lisa Scott-Trautman, Bill Murphy, Kristin



From left, Purdue University students Ali Modara, Helen Kang, Rich Sun, and Michelle Jackson, creators of Swish!

Chmela, Lee Caggiano, and Joe Donaher. Between them, they are creating a fun, entertaining, and highly educational DVD for kids ages 7-11, with much serious work behind the light-hearted approach.

The SFA team has been working throughout the year on the concept and script and on videotaping children

*Continued on page 5*

Why stop at just speaking out? This year we're

# ACTING OUT

for National Stuttering Awareness Week!



Our Time company members Linda Gjonbalaj, Jonathan Greig, Corom Buksha and David Nachman,

## Theater Stages Benefit Gala for National Stuttering Awareness Week

If actions speak louder than words, this year, the message of the Stuttering Foundation and others should be loud and clear.

Our Time Theatre in New York City is hosting a gala to mark National Stuttering Awareness Week, May 10-16. Participants will celebrate May 10

with cast members of STOMP, musical director Everett Bradley, host actress Jane Alexander, the Our Time Teens, special honoree Dr. Alan Rabinowitz, and SFA president Jane Fraser, among others.

"This marvelous event is a kick-off

*Continued on page 3*

## Genetic Studies Gain Ground

With the publication of a study in the *American Journal of Medical Genetics*, understanding of the genetic causes of stuttering has moved one step forward.

The report, entitled "Results of a Genome-wide Linkage Scan for Stuttering," demonstrates that a gene on chromosome 18 in humans can have a strong effect on the development of persistent stuttering. While the gene itself has not been identified, this study demonstrates that inherited

factors in stuttering are significant enough that it's possible to identify specific genetic factors.

"While we have a way to go before we can identify this gene, we are encouraged that progress is being made," said Dennis Drayna, Ph.D., senior author of the study. Dr. Drayna is pursuing his studies at the

National Institute on Deafness and Other Communication Disorders, part of the National Institute of Health in Bethesda, MD.

*Continued on page 7*



## Empowered Speech Triumphs Over Lifelong Stuttering

Joy Emery, 64, has stuttered for most of her life. But she delivered the commencement address in clear, fluent sentences that so captivated her audience that they sat in utter silence before erupting in applause as she reached her triumphant conclusion.

Joy has much to say on the topic of empowerment, the subject on which she was asked to speak at the graduation at the College of St. Rose in Albany, NY. That she was able to say it so well is a tribute to her own “tremendous recovery” over the speech disorder that, in her words, significantly curtailed her life.

“Empowerment comes from taking good risks and making a few mistakes in order to gain success,” Emery told graduates and guests gathered on December 20. “Don’t be afraid to make mistakes; you’ll probably make quite a few before you’re through. Most of us do.”

The words were especially poignant, because until 10 years ago when she was referred to the college’s fluency program, Emery was so afraid of making mistakes that she avoided speaking to anyone other than family.

“In the past, stuttering dominated my life, because I experienced so much fear, embarrassment, shame and exhaustion,” Emery said in

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**“I allowed stuttering to dictate my social life, who my friends were and how I spent my time.”**

---

her address. “I felt different from all of my peers and so I developed a cozy little place called my “comfort zone” which gave me protection, a predictable life, and insulated me from the pain of making mistakes. I felt imprisoned with deeply engrained negative feelings about my speech and, moreover, about myself.”

Emery credits the fluency program at St. Rose with empowering her to not only say what she wanted to say, but also with giving her a sense of freedom and the confidence to take on

leadership roles. She is particularly grateful for Dr. Charleen Bloom and Dr. Donna Cooperman, professors in the Department of Speech Sciences and Communication Disorders.

“Our approach is a synergistic one,” explains Sister Char, the preferred title of the Sister of St. Joseph. “We integrate fluency shaping and stuttering modification, and we integrate speech and language components, attitudinal components and environmental components. We believe that you can’t do a program without



Joy S. Emery, who has stuttered for nearly 64 years, was the keynote speaker at the College of St. Rose, Albany, NY, commencement. She received an honorary doctorate.

that.”

This holistic approach to speech therapy has been in existence at the college since Bloom initiated the program in 1971 with a group of about 19 people. A weekend workshop each March for those who stutter, now in its 29th year, was added next, followed by teen and children groups, a parent group, and the addition of a sibling group this year. The groups embrace both self-help and therapy practices, notes Sister Char, who has managed the program largely on her own. Two years ago, she was joined by Dr. Cooperman, with whom she has co-authored a textbook based on this model. (*See Books*, page 12.)

Joy, who began as a client at the college’s Pauline Winkler Center, now team-teaches the graduate fluency class.

“She was severe,” Bloom says of

Emery’s speech when she started, “We worked on fluency targets as well as all the attitudes. She’s to the point now that she’s gone from hiding from people to being in leadership roles within the community and Council, with the SFA and other places. She’s been teaching the class with us for about eight years. The students get a great mix. Everything we teach about stuttering, Joy explains how it affects her life.”

The support group, whose membership is fluid, was important for her own sustained fluency, says Joy, who had been through a number of other programs, beginning in childhood. After early failed attempts at therapy—which included changing her orientation from left-handed to right and then back again and a program in which she was taught to speak and chew gum at the same time—Joy avoided therapy until she was in her 40s. A three-week precision fluency-shaping course worked briefly, but without lasting effect.

“I came back fluent, but I fell right back,” Joy says. “The College of St. Rose started me with a very low hierarchy: easy speaking situations, gradually getting tougher and tougher all the time. What they did was to work on my fluency so that I was stable. At the same time, we had a self-help group where I was able to practice my fluency.”

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**“Not in my wildest dreams did I expect that my journey to fluency would lead to a 180° change in my life.”**

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Simultaneously working on attitudes and feelings as well as communication and socialization skills made the difference, Joy says. “The environmental component helped me to understand the family situation, and the team teaching—telling my story—helped a great deal. As a result, I gained a tremendous fluency, but also a tremendous recovery.”

Still, what made Sister Char sug-  
*Continued on page 5*

## SFA Board Member Helps Establish World's Largest Tiger Reserve

We have long said that “if you stutter, you’re in good company.” That’s because many of those who stutter accomplish tremendous things in life.

Take, for example, the establishment of the world’s largest tiger reserve, accomplished this March under the leadership of SFA Board member Alan Rabinowitz, Ph.D., director of the Science and Exploration Program at the Wildlife Conservation Society (WCS).

The government of Myanmar, formerly Burma, recently announced the creation of the reserve, which covers a land area nearly as large as Vermont. It’s a project Rabinowitz has been working on for 10 years.

National Public Radio’s Renee Montagne interviewed Rabinowitz for a special that aired March 15 on *Morning Edition*. (Interview and photos available at [www.npr.org/programs/re/archivesdate/2004/mar/tigers/](http://www.npr.org/programs/re/archivesdate/2004/mar/tigers/)) An article also appears in the April, 2004, issue of *National Geographic* magazine.

Rabinowitz’s many visits to Myanmar’s Hukwang Valley—as well as his struggle with stuttering—are detailed in his book, *Beyond the Last Village*. (Island Press, see *Books on page 12*.)

His first visit was in 1993, and in 1999 he surveyed the tiger population, using “camera traps” to capture on film the big cats, of which probably only 100 now remain. He also began working with the country’s national parks department to create, then expand, the wildlife sanctuary.

Although the announcement is a tremendous step forward, the “really hard work,” according to Rabinowitz, is actually just beginning. He plans several more trips to Myanmar to work out details on funding, wildlife man-



agement strategies and how the WCS and Myanmar’s forestry department will work together to make the world’s largest tiger reserve a reality.

This is not the first reserve that has resulted from the zoologist’s efforts.

The Society’s web site ([www.wcs.org](http://www.wcs.org)) documents work done by Rabinowitz and the Society’s Jaguar Conservation Program team to establish a safe corridor for jaguars spanning 14 countries, from Arizona through Central America and into northern Argentina.

*In Search of Jaguars*, a National Geographic Special that aired this past November on PBS stations nationwide, also documents the team’s efforts to protect the endangered cats.

The efforts are paying off. Rabinowitz will be part of a ceremony this June in Costa Rica, dedicating a wildlife sanctuary there as part of the “necklace” or corridor of protected wild places the elusive cats call home. □



Alan Rabinowitz tags a jaguar. His work in Belize resulted in the first sanctuary for the cats.



## our time

*Continued from page 1*

to celebrate everyone’s efforts to increase awareness.” said Fraser, who will be introducing Rabinowitz, SFA Board member and this year’s Our Time Award winner. “Alan is an outstanding spokesperson for NSAW 2004. It’s exciting to see so much of his hard work in other areas of his life coming to fruition this same year.” (See related story, this page.)

The evening begins with a cocktail reception at 6 p.m. at the Andavi Cafe, then moves to the Lucille Lortel Theater for an 8 p.m. performance by the Our Time Teens, the cast of STOMP, Adam Pascal, Alice Ripley, and musical director Everett Bradley.

Our Time Theatre is a nonprofit organization dedicated to providing an artistic home for young people and adults who stutter.

The purposes of this event are manifold,” said Artistic Director and founder Taro Alexander. “We want to increase awareness about Our Time Theatre, about National Stuttering Awareness Week, the Stuttering Foundation, and about stuttering in general.

“We want to begin the tradition of having a wonderfully inspiring, public event on the first day of National Stuttering Awareness Week where people can come together and celebrate. In short, we want to start the week off with a bang. It’s also a chance for the teenagers at Our Time to speak publicly about the challenges that face

*Continued on page 7*

**New Stuttering Awareness poster features Alan Rabinowitz. Great for your clinic, community, school, library, or workplace. Order online or call 1-800-992-9392.**



# From Washington to Kenya: A Journey for Fluency

By Barbara Mathers-Schmidt, Ph.D.

*“Dear Barbara,  
Asante sana kwa kuni julisha ya  
kuwamaba ni na waza kapona.  
Ni mimi wako,  
Kevin O.”*

This handwritten message was given to me by Kevin, a 14-year-old boy who lives in an orphanage in Nakuru, Kenya. Through an amazing series of events, I got to know this young man who has a severe stuttering disorder. It was an experience that deeply touched my heart and one I hope will change Kevin’s future.

I had been contacted months earlier by a Childcare International volunteer who wondered if I might send some information to assist Kevin’s teachers. They were perplexed by how to help this child who stuttered so severely that he rarely attempted to talk. Ironically, I was planning to travel to Kenya and was gathering books and brochures about communication disorders to share with hospital and school personnel. And so it was, that on February 13, I met with Kevin in a large, sunny dining hall, joined by his teacher, school principal, pastor, and the volunteer.

As I sat down with Kevin, I asked his teacher to interpret the letter Kevin had written before my arrival: “Thank you very much for informing me that I can be healed with my speaking. Yours sincerely, Kevin O.”

Kevin spoke in English and Swahili during our time together and stuttered in both languages. Kevin referred to the disorder as “kigugumiri” or “stammering.” He explained that he had been stammering since he was about four years old. He had no idea what caused his stammering, although he did recall that one of his uncles also stammered. When I asked him if he had found anything to do that makes it easier to talk, he replied, “Not yet.” I asked how he got his ideas across when he had difficulty talking. He responded, “Go slow.” “Good idea!” I replied.

As Kevin and I talked, often with the assistance of his interpreter, I learned that when he stutters, he doesn’t know exactly where or how the sound stops, but he is aware of working hard and then getting tired. He also shared that people occasionally make fun of him,



**Barbara Mathers-Schmidt, Ph.D., and Kevin study stuttering modifications tools in *Self-Therapy for the Stutterer*. Kevin, who lives in Kenya, never knew there was help for those who stutter. Barbara’s trip to Kenya included sharing much-needed resources donated by the SFA with schools and hospitals in the region.**

or treat him in a way that makes him feel uncomfortable.

“Did you know that three million Americans stammer?” I exclaimed.

A smile broke across Kevin’s face. I showed him the photographs of famous people who stutter: His teacher and pastor nodded in astonishment. I explained what we know about stammering—that people who stutter seem to be born with a neurophysiological predisposition to stutter, and that stuttering seems to be genetically transmitted in many cases. We discussed how many thousands of messages travel from the brain to our muscles to allow us to breathe and move for speech. I explained that somehow, as some people go from an idea to shaping sound into speech, they sometimes stammer.

**“Almost everyone knew someone who stuttered, and, without exception, they had the misconception that nothing could be done to help.”**

Kevin had hoped that I would be curing him of this “problem.” I explained that I would not cure him, but would show him how he could learn to make speaking easier. We practiced “easy speech” techniques. I then showed him the *Self-Therapy for the Stutterer* book, and reviewed the stuttering modification techniques, so that Kevin and his teachers would be well

prepared for their work together.

Only months before, Kevin had been living on the streets. He was addicted to sniffing glue, and he rarely spoke. He now lives in a comfortable residential setting with adults who care deeply about his well-being and his extraordinary potential. This bright, appealing boy readily engaged in the discussion about stammering and seemed relieved as he learned more about a problem that had made him feel so hopeless.

The school personnel likewise were surprised to learn that something can be done to help those who stammer. They adeptly participated in considering strategies to help Kevin. They will begin by reviewing materials donated by The Stuttering Foundation and will be meeting regularly with Kevin to practice fluency skills.

While in Kenya, I visited six other schools in somewhat remote areas of the Central District. The schools ranged from a private boarding school with a relatively well-equipped computer lab to a four-room secondary school with dirt floors and no electricity. Part of my mission was to discuss stuttering with the headmasters and leave resource materials donated by The Stuttering Foundation. It was not surprising that almost everyone knew someone who stuttered, and, without exception, they had the misconception that nothing could be done to help. In each case, teachers and administrators were eager to learn, and welcomed the information provided by the Stuttering Foundation.

Through e-mail, Kevin’s teacher and I continue to work together to help Kevin. Kevin happily agreed to report back to me about how he is doing. He is eager to correspond with a 14-year-old American boy who stutters.

As we moved toward the end of our time together, it was a joy to hear Kevin chuckle before he used fluency shaping and stuttering modification techniques on one of the few Swahili phrases I know: “Hakuna matata!”\*

*Barbara Mathers-Schmidt, Ph.D., is a professor in the Communications Sciences and Disorders Department at Washington Western University, Bellingham, WA.*

\*Don’t worry, no problem! □



### Empowered Speech

*Continued from page 2*

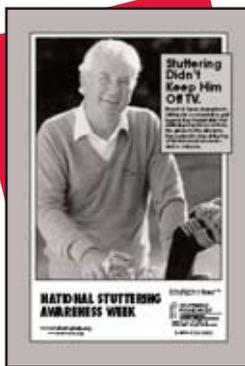
gest Joy as a commencement speaker?

“I didn’t, the president recommended her,” Bloom responds. “He [Dr. R. Mark Sullivan] said, ‘How do you think Joy would be. Do you think she could do it?’ I said, ‘I’m sure she could!’ When it was over, all 2000 people stood and gave her a standing ovation. It was so moving and she did it so well.”

Contact Sister Charleen Bloom at 518-454-5122 or Dr. Donna Cooperman at 518-458-5357. The St. Rose program is open to children, teens, adults, parents and siblings. SLPs are welcome to observe.

For information about other programs, go to [www.stutteringhelp.org](http://www.stutteringhelp.org) and click on Resources, then Referrals. Programs are listed by state and/or country. □

## “Mr. 59” and Ken Venturi Score with Palm Desert Golf Benefit for SFA



SFA poster with Ken Venturi promoting stuttering awareness.

Play a few rounds, soak up the sun in Palm Desert, and sip champagne with golf legends Ken Venturi and Al Geiberger—

and donate to charity at the same time?

The annual “Mr. 59” Golf Invitational

hits a hole in one with this plan!

Thanks to the efforts of Bob Foote and Ken Venturi, the Stuttering Foundation was one of three charities which benefitted from Al Geiberger’s 20th Annual Invitational at the Desert Falls Country Club on April 23-24.

Ken Venturi, past chairman of National Stuttering Awareness Week, was this year’s honoree at the tournament, hosted by Geiberger.

“On June 10, 1977, Al Geiberger shot a score of 59 in the Danny Thomas golf tournament,” said Bob Foote, assistant tournament organizer and longtime friend. “The score of 59 was the lowest competitive round by any pro golfer ever. It was a remarkable achievement. So, some friends of Al’s started this tournament to celebrate that sensational score. Part of the

tournament is to raise money for several of Al’s favorite charities. This year, the Stuttering Foundation is one.”

Foote, a competitive amateur golfer who has played in the tourney for the past 15 years, also stutters so had much in common with Venturi.

“It’s really through Ken Venturi that we’re making a contribution to the Stuttering Foundation. I had lunch with Ken and Terry Cole [tournament organizer] and he discussed his experiences as a teenager with stuttering, and how he worked through it and then became a CBS commentator.”

The invitational brings together 130 players over three days, playing two courses in what has long been a mecca for golf aficionados.

And after the play, there is play!

Clinics and demonstrations. A glittering banquet with singers, entertainers, and comedians. A silent and live auction. Roasts and toasts.

“It’s an all-around wonderful three days of golf,” Foote agreed.

It’s also an all-around wonderful way to help those who stutter.

The Stuttering Foundation thanks all participants. (Final results and pictures in the next newsletter.)



The cover of 1964 Sports Illustrated.

## Swish Scores With Kids Who Stutter in New DVD

*Continued from page 1*

who stutter. The students at Purdue, for whom this is a senior project, have thoroughly researched the “human application”—what works for kids in grades 2-6 as far as memory retention, characters they relate to, attention span, ad infinitum.

The background research had to be rigorously defended to a board of professors before Swish got past the sketchbook stage, according to Ali, a senior from Bahrain who dreams of becoming “the Steven Spielberg of the Middle East.”

“To create Swish, the first step is concept art, drawings and storyboards

all by hand. The next step is to model him using a 3-D program like MAYA,” says Ali. “Because he’s a basketball, we create him in a series of spheres. Texturing is the process of taking the material the character would be made of and slapping it on him—skin like a basketball, eyeballs. It’s the texturing that gives personality.”

The result of this wizardry is Swish, a bouncy, genderless, cartoon with a kid’s voice and vocabulary, who pops in and out of the video, asking questions such as, “Does stuttering ever bug you?” that are answered by children who stutter.

Who can resist?

“Not kids who stutter, if our research is right,” said Michelle, an interactive multimedia development major whose computer coding skills, combined with animation, bring Swish to life.

“I’m primarily here to work in the human research subjects,” Michelle added. “We have to test this on children to see if they like Swish and see if it works. That’s ultimately what we want—for it to be effective.”

To ensure that Swish is, he’ll be field tested with children in the speech clinics at Purdue and Florida State University. *Continued on page 12*

## Actor's Ongoing Support for Stuttering



Once again, Nicholas Brendon fans are reaching out to wish Nick a happy birthday and to help the SFA!

Nick's birthday is April 12, but you can still contribute after that date and be part of the Nick Brendon Birthday Project 2004. More importantly, you can still directly help those who stutter, and wish the actor a happy birthday at the same time.

Nick has a lot going on right now, with a new made-for-TV movie, *Celeste in the City*, that aired in March on ABC family, and other projects. (Check it all out at his Web site, [www.NickBrendon.com](http://www.NickBrendon.com).) Still, he's always been right there for others who stutter through his support of and outreach for the SFA.

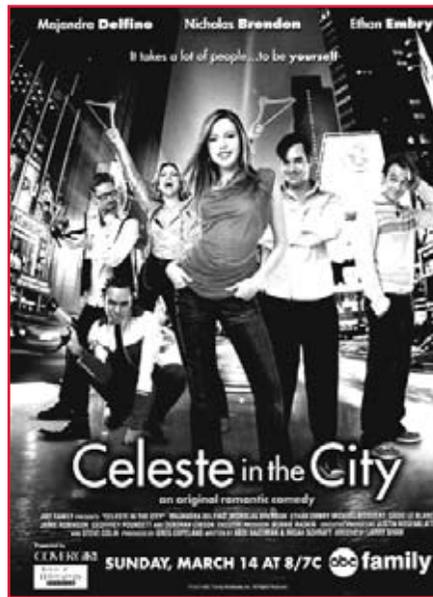
Since 2001, Nick has served as a spokesman for the Stuttering Foundation of America. In that time, visitors to his Web site have contributed more than \$5,000 to The Stuttering Foundation.

Helping the SFA has been a very significant outcome of Nick's role on *Buffy the Vampire Slayer*. Here's our chance to acknowledge all he's done!

To donate electronically go to the SFA's Give Page online at [www.stutteringhelp.org](http://www.stutteringhelp.org). Or give by phone and credit card by calling 1-800-992-9392.

By mail, you may send a check to: The Stuttering Foundation, 3100 Walnut Grove Road Suite 603, P.O. Box 11749, Memphis, TN 38111-0749.

Please indicate that your gift is associated with the Nick Brendon Birthday Project.



Stanford Dean Piazza and Gina Perez-Baron.

### Stuttering Doesn't Stop Me

I am a third year medical student at Stanford University School of Medicine. I don't know how much I would say I've "overcome" stuttering, but it no longer stops me from pursuing the life I want.

I stuttered terribly as a child. I'd try to hide it or sit in silent frustration as someone else stood up and claimed my words. As a teenager, my speech improved but I still hated it and, at times, hated myself for it.

I was in my twenties when something shifted. Sick and tired of stuttering and feeling sorry for myself, I saw an ad about a "cure" for stutterers. Great! Then I found the cost, \$2,500. I had to find another way.

So, I started trying to accept my stuttering. Accept. Now, there's a word that really stuck in my throat! But what else was there? Slowly, I tried hiding it less. I tried announcing, "I stutter" when the struggle got too great. I stopped avoiding telephone calls. I started speaking up.

Sometimes my speech was smoother. Sometimes people noticed it less. I still stutter, but I'm not Elmer Fudd. People tell me it takes a while for them to even notice.

I've taught myself a few strategies that help. Public speaking remains the worst. But today, it's just my unique "thing." And I see that everyone's got their own "unique thing"—something to struggle with, to overcome.

These days, stuttering doesn't hold me back so much; I'm not so afraid. And fear was, and remains, my biggest obstacle. Getting past that, I'm able to do the things I need to so I can be what I want to be.

*Gina Perez-Baron is a student at Stanford University School of Medicine. Her poem is at newsletter at [www.stutteringhelp.org](http://www.stutteringhelp.org)*

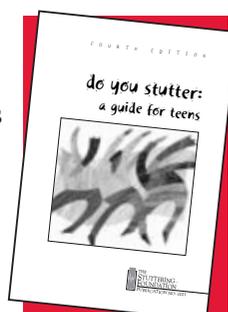
## Updates Reflect New Gains in Knowledge

### Book for Pediatricians

■ A new edition by Barry Guitar, Ph.D., the University of Vermont, and information reflecting the latest neurological and genetic research introduces the subject of stuttering in the new third edition of *the child who stutters: a guide for pediatricians*. Book 0023, which includes a useful chart to help determine the need for early intervention, is available from the SFA for \$2.00 or may be downloaded for free.

### For Teens

■ Teenage years can be tough, especially for someone who stutters. *Do You Stutter: A Guide for Teens* offers real help to



make life better. Book 0021, a 72-page book, is available for \$2.00 by catalog or online.

### If You Think Brochure

■ *If You Think Your Child is Stuttering* is packed with information to help parents understand the difference between normal disfluency and stuttering. With the addition of a risk factors chart and a "How to Help Right Away" section, the brochure is even more useful for parents trying to help their child immediately, while determining the need for professional intervention. "Seven Tips for Talking" offer excellent advice on speaking to any child. Brochure 41 may be downloaded free; \$8.00 for 100 copies.

Risk Factors Chart		
Risk Factor	What to look for	True for my child
Family history of stuttering	A family member who still stutters	
Age at onset	After 3; 1; 2	
Time since first noticed stuttering	Stuttering 6-12 months or longer	
Other speech-language history	Speech errors, trouble following directions	



Donny Sethl works on a song with musical director Everett Bradley. "If I don't talk, they take a part of me," says the Greenwich, NY teen.

### Acting Out for NSAW

*Continued from page 3*

young people who stutter. And of course, we need to raise a little bit of money."

Taro's experience as a person who stutters, combined with the transformative power of theatre, compelled him to create Our Time. A successful actor himself—now in the cast of the off-Broadway production of STOMP—Taro's goal is to help others who stutter find a safe place to express their creativity, to find their voice in performing.

Members study acting, singing, playwriting, drumming and dance with professional artists. No performance experience is required and there are no fees to join, hence, in part, the reason for the benefit.

"Our Time provides an environment free from ridicule where young people who stutter discover the joy of creating and performing original theatre," notes gala host Jane Alexander, Emmy-award winning actress of film, stage and television. Alexander first won acclaim for her Tony-winning role in *The Great White Hope* with actor James Earl Jones, who also stutters.

"Our Time provides a powerful way for the audience—families, friends, professionals—to begin to feel and understand the challenge of those living with stuttering," said Lee Caggiano, executive director of Friends: The Association of Young People Who Stutter. "Taro Alexander has given voice to stories that might otherwise have gone untold."

For more information call or email Our Time at 212-414-9696 or [moreinfo@ourtimetheatre.org](mailto:moreinfo@ourtimetheatre.org) or SFA at [info@stutteringhelp.org](mailto:info@stutteringhelp.org). □

## News Shorts

### Invest in Kids Selects SFA Web Site as a "Five Star" Resource for Parents



■ "Our experts at Invest in Kids have selected your web site, [www.stutteringhelp.org](http://www.stutteringhelp.org) as an important resource of parents of children under five!" wrote Chris Geady to tell us about their "Five Star Recommendation" of SFA's site. Invest in Kids is a non-profit organization which helps families make the most of their children's first five years: "The years before five last the rest of their lives." □

### NSSLHA Chapters Donate

■ Thanks to the University of North Kansas and Nicholls State University chapters of the National Student Speech-Language Hearing Association, which recently sent gifts to the SFA. Nicholls State is in Thibodaux, LA, and UNK is in Kearney, NE. □



### New Album, "RightFully Spoken" for PWS

■ Frankie Jones has released a new CD, "RightFully Spoken," for those who stutter. "I am a PWS and have dedicated my music and life to uplifting and motivating those who stutter," writes the Lincoln, NE, musician. A popular performer in public schools, Frankie's single, "Man in the Mirror" is well-known in the stuttering community. For information, call the SFA at 1-800-992-9392.



The Stuttering Foundation of America is a tax-exempt organization under section 501(c)(3) of the Internal Revenue Code and is classified as a private operating foundation as defined in section 4942(j)(3). Charitable contributions and bequests to the Foundation are tax-deductible, subject to limitations under the Code.



### SA Scholarship Benefits PWS Down Under

■ The International Stuttering Association in Perth, Australia emailed its thanks for all those who contributed to their scholarship fund, and sent a photo of everyone from outside Australia who was able to attend their gathering. "I am sure that your contribution will not be forgotten in a lot of places around the world," writes Stefan Hoffman of the ISA. "Thanks again." □

### Genetics Gain Ground

*Continued from page 1*

While his recent study involved more than 50 families from across North America, Drayna is pursuing additional studies elsewhere in the world. A previous article in the SFA newsletter documented one family under study in Cameroon, West Africa, and recent efforts have taken Drayna to Pakistan, where the high number of cousin marriages present particularly favorable conditions for genetic studies of stuttering.

Drayna cautions people not to expect quick cures from this research. "Our goal is to use genetic studies to understand at least some of the underlying causes of stuttering. While not all stuttering is genetic in nature, we look forward to unraveling this part of the puzzle of stuttering, which will hopefully lead to better treatments in the future," he notes. □

### Upcoming Workshops

Two-Day Workshop  
**Stuttering Therapy: Practical Ideas for the School Clinician**

■ June 11-12, 2004 in Cincinnati, OH

Two-Week Workshop  
**Stuttering Therapy: Workshop for Specialists**

■ June 2005 in Iowa City

■ All Five-Day Workshops are filled

Applications may be downloaded from [www.stutteringhelp.org](http://www.stutteringhelp.org) or call 1-800-992-9392

## Letters: Reader Response to Survey on Electronic Devices

Dear SFA:

If the SpeechEasy is being marketed as a cure, that is wrong, but as a tool, I find it very helpful. I spoke today at lunch to a large group of advertisers. It helped me to control my gentle onsets more effectively and I had fewer blocks than usual. I realize those in search of the magic pill will be disappointed, but as a tool, it is immensely valuable to me.

I complained of its price, also, but I'm comfortable the company has invested much in its research beyond the manufacturing cost of the device.

My clinician, Helen Duhon of Franklin, Tenn., thought long and hard before she began handling the device. She is a Vanderbilt speech therapy grad who is trying to interest them in further study of the device.

You are wise to warn against the device as a "cure," but as a tool I think it has much to offer. The SFA performs a valuable service and there are scams out there to be wary off. I don't think the SpeechEasy device is one of them—but it certainly is not a cure.

Vince Vawter, IN

Editor, *Evansville Courier & Press* □

Hi SFA,

I am a school based SLP, employed by an intermediate school district. We have had many parents of children who stutter interested in auditory feedback devices. Our assistive technology department has decided to purchase a Fluency Master for a student through Michigan State University.

I have a great interest in stuttering and have agreed to analyze and provide data for the ISD to determine the effectiveness of these devices. Personally, I do not think it is wise for schools to purchase these device, as they may be unleashing something they cannot control. They are costly devices that have little empirical evidence that support their efficaciousness.

I am reviewing and analyzing videos of the students before the Fluency Master, at the introduction of the Fluency Master, and 2-3 months after initial use.

Alisa MacDonald, M.S., CF-SLP

Battle Creek, MI □

Dear SFA:

The Winter 2004 edition of SFA's newsletter reported the results of a survey that appeared largely critical of the appeal

and effectiveness of electronic auditory feedback devices. While the article included quotes from satisfied users, including those who had used their device successfully for more than a year, the overall gist was that electronic auditory feedback devices are in fact not a "magic bullet."

As the president and CEO of one of the leading providers of such devices, it may come as some surprise that I agree with this conclusion... electronic devices are not a "cure" for stuttering. Instead, they offer a technologically advanced treatment option that can help people who stutter speak more fluently with less effort. As such, it is important that anyone considering such a device be able to separate fact from fiction.

A key to clearing up misconceptions about these devices is to understand where they fit on the continuum of available treatment options. Stories in the news media tend to provide an oversimplified view, proclaiming AAF devices as "miracle cures." As speech fluency professionals, we must do a better job communicating the benefits and limitations of AAF devices. To this end, new and upcoming research data published in peer-reviewed scientific journals provides some valuable insight.

A study published last year in the *International Journal of Language Communication Disorders* (Vol. 38) tested the efficacy of the device called SpeechEasy, which was referenced in SFA's previous newsletter article. The study subjected seven users to a variety of tests, and reported that the device reduced stuttering significantly while helping to produce speech that was more natural.

While the study provides many valuable answers, it also raises some questions. Foremost among these is the long-term efficacy of such devices, given that the study subjects were followed for just four months after being fitted.

What the already reported data shows is that when used in conjunction with conventional therapy, the SpeechEasy AAF device enhances the rate of progress among patients, and is a valuable new tool for SLPs to consider in concert with other therapeutic options.

Darwin Richards

CEO, Janus Development Group

(SpeechEasy) □

Dear SFA,

I commend your survey about electronic anti-stuttering devices. However, the survey showed that persons who stutter have misconceptions about the devices.

The most common reason cited for not buying a device was "expense/lack of insurance." Since 1992, Casa Futura Technologies has helped every American consumer who has needed every devices, regardless of his or her ability to pay. Survey results included a complaint about a "\$700-800" fee and "90% money-back guarantee" apparently charged by another company. Casa Futura has always offered a 60-day, 100% money-back guarantee.

Respondents "cited concerns over lack of long-term research on devices." The *International Journal of Language and Communication Disorders* (2003, Vol. 38, No. 2, 119-129) recently published a long-term study of our least expensive devices. Researchers tested nine severe adult stutters before using the devices, and again three months later. The subjects used the devices about thirty minutes per day. The subjects' stuttering diminished 50%, without any other speech therapy.

One respondent complained about his device being difficult to use in noisy environments. Hearing safety is a paramount concern. Users who experience ringing in their ears or headaches should discontinue using their device and get their hearing checked. It's also possible that overuse of an anti-stuttering device could cause a child's auditory processing to develop abnormally. To minimize hearing impairment, anti-stuttering devices have a variety of noise-reduction features.

The last comment was telling. A mother wrote, "I'm most disappointed. It wasn't a quick fix. Since it wasn't, [my son] quit using it." That isn't the device's fault! Successful stuttering treatment requires hard work over a long time. The devices can be of great value when used as part of a larger stuttering therapy program. Anyone looking for a "quick fix" is likely to be disappointed.

Thomas David Kehoe

Owner, Casa Futura Technologies □

*Editor's Note: The Stuttering Foundation of America welcomes your response; however, due to space constraints, we reserve the right to edit articles for length. Address your letters to info@stutteringhelp.org or The Stuttering Foundation, 3100 Walnut Grove Road, Suite 603, Memphis, TN 38111.*

# Seminars Attract Hundreds to Learn About Stuttering

Packed rooms, enthusiastic participants and engaging speakers have gathered around the country to learn about stuttering. SFA has been there to help, including, at press time, a trip to San Antonio for the Texas Speech-Language Hearing Association conference.

In Long Beach, CA, SFA's Deborah Squires and SLP Liz Brown manned a busy table at the L.A. United School's conference on stuttering. The event drew nearly 600 speech-language pathologists.

About 700 SLPs—a record number—attended the annual conference sponsored by the The University of Memphis chapter of NHSSLA, with guest speaker Bill Murphy, Purdue University. SFA staffers Laura Beauchamp and Lorissa Hatcher hosted a booth in SFA's hometown in March.

"We sold out of lots of things and had to run back to the office for more, in-

cluding *If Your Child Stutters: A Guide for Parents*, *The School-age Child Who Stutters: Working Effectively with Attitudes and Emotions*, *Integration of Contemporary Therapies*, *Sometimes I Just Stutter*, and *magnets*," Hatcher said.

SLP June Haerle-Campbell and her husband, Allen, represented the SFA at the California Speech-Language Hearing Association annual conference in March in Long Beach. Workbooks and magnets were hot items, disappearing quickly from the booth, which also drew people simply to thank the SFA for providing such affordable materials.

March 5 -6, the Tacoma Public School District and

the Tacoma/South Puget Sound chapter of the NSA sponsored a workshop for therapists, followed by a Family Day.



Vivian Sisskin, of the University of Maryland, spoke March 5 on "Problem Solving in Stuttering Therapy," attended by about 350 SLPs from Washington state.



The fluency game's in the bag for Garrett and Robert in SLP Mary Turcotte's group on Family Day at Tacoma's two-day event, March 5-6.

The SFA was invited to have a table of publications at both.

On April 3, Charley Healey, University of Nebraska, spoke at the Oklahoma state gathering in Edmonds.

SLP Darla Benoit volunteered to man a table of SFA publications.

"It was fun working at the SFA table and hearing all the positive comments about the Foundation," Benoit said. "I'm so proud and grateful to be involved with it."



SLPs Doug Wing and Connie Haines of Tacoma, WA.

Lisa Scott Trautman, Florida State University, spoke in St. Louis, sponsored by *Friends*. Lisa talked about the CALMS model, answering questions and personalizing the talk to meet therapist's needs, reported SLP Susan Short. Lee Caggiano spoke to parents on Stuttering 101, and Lee, Irene Bullard and Susan facilitated parent roundtable discussions.

Barry Guitar, University of Vermont, distributed SFA material when he spoke in Norfolk, VA, at a conference organized by Kim Stallings, former SFA Workshopper. □

## Annual Audit of Foundation by KPMG

The annual audit of The Stuttering Foundation financial reports for 2003 was recently completed by the accounting firm of KPMG. Following is a recap of funds and expenditures for the year.

The 4.0% of expenditures for ad-

ministration and general expenses and the 6/10 of 1% for fund raising are very low, and since we are fortunate to have an endowment which more than covers our overhead expenses, donors can be assured that their gifts will go directly to support our program services.

### Funds expended for:

Creation, production, printing and distribution of educational materials	\$556,589	49.8%
Public information and education	\$236,261	21.1%
Educational symposia for professionals and research	\$176,695	15.8%
Maintain Web site and toll-free stuttering information hotline	\$ 96,902	8.7%
<b>Total for Program Services:</b>	<b>\$1,066,446</b>	<b>95.4%</b>
Other expenditures:		
Administration and general	\$45,000	4.0%
Fund raising expense	\$6,934	.6%
<b>Total Expenditures:</b>	<b>\$1,118,386</b>	<b>100.0%</b>

The Stuttering Foundation of America is a private operating foundation which expends its funds on its own programs and does not make grants to other institutions.

## Give the United Way

You can donate to the Stuttering Foundation directly through the United Way. Direct designation allows you to specify your gift to the SFA. Proof of nonprofit status can be sent to your employer by fax, mail or email.

## NEWS BRIEFS

■ The Stuttering Foundation two-day conference for speech-language pathologists working with school-age children who stutter, *Practical Ideas for the School Clinician*, will be held June 10 and 11, 2004, in Cincinnati. For an application form, contact the Stuttering Foundation at 1-800-992-9392 or download it directly at [www.stutteringhelp.org](http://www.stutteringhelp.org).

■ The Stuttering Foundation Western Workshop, *Diagnosis and Treatment of Children who Stutter: Practical Strategies*, directed by Susan Hamilton, M.A., Jennifer Watson, Ph.D., with David Prins, Ph.D., will be held at the University of Washington, Seattle, June 23 - 27, 2004.

■ The Stuttering Foundation Southern Workshop, *Diagnosis and Treatment of Children Who Stutter: Practical Strategies*, directed by Lisa Scott Trautman, Ph.D., Kristin Chmela, M.A., and Joe Donaher, M.A., will be held at Florida State University, June 23 - 27, 2004.

■ The Stuttering Foundation two-week *Workshop for Specialists* will be held at the University of Iowa, Iowa City, Iowa, in June, 2005, directed by Patricia Zebrowski, Ph.D. and Toni Cilek, M.A. For more information, contact the Stuttering Foundation at 1-800-992-9392, or write Dr. Zebrowski, c/o SFA, 3100 Walnut Grove Road, Suite 603, Memphis, TN 38111-0749. This unique workshop brings together speech-language pathologists from all over the world.

■ *Clinical Training in Lidcombe Program: A Behavioral Intervention in Stuttering for Young Children*. This workshop featuring Elisabeth Harrison will be held June 16-18, 2004, at the University of Vermont. For more information, please contact Rosalee Shenker at the Montreal Fluency Centre, [rosalee@montrealfluency.com](mailto:rosalee@montrealfluency.com).

■ FRIENDS, The National Association of Young People Who Stutter, will hold their annual convention in the San Francisco Bay area from July 22-24, 2004, at the Marriott Hotel at the San Mateo/San Francisco Airport. Please contact FRIENDS2004SF@aol.com or 1-888-866-8335 for information. A registration brochure can be downloaded from the website [www.friendswhostutter.org](http://www.friendswhostutter.org).

■ To participate in a study on client satisfaction with stuttering therapy, please contact Walter Manning, Ph.D., at [wmanning@memphis.edu](mailto:wmanning@memphis.edu).

■ For those wanting to purchase a poster entitled *The Bill of Rights and Responsibilities of PWS*, contact Michael Sugarman at [MSugarman1@aol.com](mailto:MSugarman1@aol.com). It represents the combined effort of the IFA and ISA.

■ LISTSERV for doctoral students specializing in stuttering. The intent of this list is to serve as an open forum for doctoral students. Membership is limited to doctoral students only. To subscribe, send the following message to [listserv@listserv.temple.edu](mailto:listserv@listserv.temple.edu): subscribe stutterdoc firstname lastname" or contact Joe Donaher at [turtlecraw@aol.com](mailto:turtlecraw@aol.com).

■ For those interested in joining Toastmasters International as a way to improve fluency,

communication or public speaking skills, their address is: Toastmasters International, Inc., Attention: Membership Department, P.O. Box 9052, Mission Viejo, CA 92690, Telephone: (714) 858-8255; Fax: (714) 858-1207.

■ For those wanting to obtain a copy of *Self-Therapy for the Stutterer in Japanese*, write to Dr. Shokichi Nakajima, 2-21-1 Ogawa Machida-shi, Tokyo 194, Japan, telephone/fax: 0427 (96) 5092.

■ *Self-Therapy for the Stutterer* is available in French. Write to the Association des Begues du Canada, 2596 A rue Chapleau, Montreal, Quebec, Canada, H2K 3H6; 1-877-353-1042. Please enclose \$20.00 Canadian to cover printing, postage, and handling costs.

■ For those wanting to obtain a copy of *Stuttering and Your Child: Questions and Answers* in Hindi, write to: Dr. Sajiv Adlakha, Adlakha Speech and Hearing Clinic, A67 Dayanand Colony, Lajpat Nagar - 4, New Delhi-110024, India, or e-mail: [adlakhas@hotmail.com](mailto:adlakhas@hotmail.com) Those interested in joining a fluency and public speaking skills group should also contact Dr. Adlakha at the above address.

#### Books on Stuttering or Related Topics Available from Bookstores:

■ *Understanding Stuttering*, Nathan Lavid, M.D. Available by calling 800-737-7788. University Press of Mississippi, Jackson, MS; [www.upress.state.ms.us](http://www.upress.state.ms.us). 2003.

■ *Beyond the Last Village and Jaguar: One Man's Struggle to Establish the World's First Jaguar Preserve* by Alan Rabinowitz. Available from Island Press, Washington, D.C.; [www.islandpress.org](http://www.islandpress.org).

■ *Stuttering Therapy: Rationale and Procedures* by Hugo H. Gregory, June H. Campbell, Diane G. Hill, and Carolyn B. Gregory. Available from Allyn and Bacon, Boston, MA; [www.ablongman.com](http://www.ablongman.com). 2003.

■ *Les begaiements: Histoire, psychologie, evaluation, varietes, traitements* by Anne Van Hout and Francoise Estienne. Published by Masson, S.A., 120 boulevard Saint Germain, 75280 Paris Cedex 06, France.

■ *Forty Years After Therapy: One Man's Story*, by George Helliesen, M.A. Available from Apollo Press, Inc., 1-800-683-9713 or on-line at [www.apollopress.com](http://www.apollopress.com).

■ *Programmed Stuttering Therapy for Children and Adults*, (2001) by Bruce Ryan, Ph.D. Available through publisher Charles C. Thomas or on-line at [www.amazon.com](http://www.amazon.com).

■ *Making a Difference for America's Children: SLPs in the Public Schools*, by Barbara Moore-Brown and Judy Montgomery. Available from Thinking Publications, Eau Claire, WI. 715-832-2488.

■ *Ben Has Something To Say* by Laurie Lears, illustrations by Karen Ritz. A book for children ages 5-9. Albert Whitman & Co., Morton Grove, IL. 800-255-7675.

■ *Sharing the Journey: Lessons from my Students and Clients with Tangled Tongues* by Lon Emerick, Ph.D., available from North Country Publishing, 355 Heidtman Road, Skandia, MI 49855 for \$13.95 plus \$2.00 postage and handling. Call toll-free 1-866-942-7898, or visit [www.northcountrypublishing.com](http://www.northcountrypublishing.com).

■ *Living With Stuttering* by Kenneth St. Louis, Ph.D. Available from Populore Publishing Company, P.O. Box 4382, Morgantown, WV 26504, 304-599-3830. □

## Swish Scores

*Continued from page 5*

The team has finished lighting the scenes for shadow and depth and heads into a week of intensive animation.

Rich is the lead animator, so it's his turn to shine, lip-syncing Ali's computer-altered voice, making sure eyebrows move, adding the hundreds of touches that make up the gigabytes' worth of memory that is Swish.

"We have 14 scenes between [live] footage segments," noted Helen, so the pace back and forth is quick.

Then it's to the desktop equivalent of a film cutting room floor for editing.

"The final thing is called rendering, and you take the animation that we have and convert it into a movie block, and then the editing and composing comes last," Ali said.

Here, Swish finally gets to meet his live friends, who together, have made this video by kids, about kids, for kids who stutter. □

## NW Workshopper's Death Leaves Loss

One of the all-time favorite workshoppers, **Andre Courcy**, died on March 15, 2004, of pancreatic cancer. Services were held in Quebec on March 19.

A member of the SFA's Northwestern University Workshop Class of 1997, Andre was remembered with fondness by workshoppers.

"I laughed so hard with him that I would have tears rolling down my eyes. I am sure his family and friends will miss him terribly," said Susan Hamilton, SLP. Donations in memory of Andre will fund a scholarship to the Workshop for Specialists. □



## STUTTERING FOUNDATION™

A Nonprofit Organization  
Since 1947 — Helping Those Who Stutter  
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