

# STUTTERING FOUNDATION

Research on DAF effectiveness

■ Teen speaks out for others who stutter

■ Salute to Mister Rogers

Synopsis on survey of parents' reactions

■ Upfront on SpeechEasy

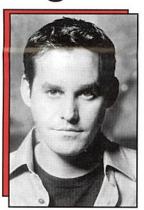
A Nonprofit Organization

1-800-992-9392

www.stutteringhelp.org

Since 1947... Helping Those Who Stutter

# NSAW in High Gear



Nicholas Brendon's celebrity status "Xander" in the TV series Buffy Vampire Slayer has helped shine the light on his effort to help children and teens who stutter.

Brendon, chair of National Stuttering Awareness Week (NSAW), has two new projects underway for NSAW, May 12-18, 2003. The Nicholas Appreciation Project benefits The Stuttering Foundation directly with donations made through his Web site, www.nickbrendon.com. And Nick is producing a public service announcement for the Foundation featuring the popular actor with an important message: if you stutter, you are definitely not alone.

These projects come even as Nick undertakes a new pilot show with Ron Leavitt (Married...With Children).

But the actor says he's never too busy to speak out on stuttering,

"Stuttering is a very lonely place to be," Nick said.

Many children who stutter do not know anyone else with the disorder—one reason that Stuttering Awareness Week materials feature 15 famous people who stutter, including Nick, and the message that, "If You Stutter, You're in Good Company."

Brendon's work is critical because many people still do not understand this complex disorder which affects over 3 million Americans.

A recent national survey commissioned by The Stuttering Foundation reveals that there is still a tremendous gap in understanding stuttering.

The survey found that nearly 90 percent of parents said "slow down and relax" is exactly what they would tell a child who begins to stutter. Yet such simplistic Continued on page 3

# TV Coverage Reaches Millions with Need for Stuttering Education



The news media's response to a national survey commissioned by The Stuttering Foundation has enabled millions of parents to learn how best to respond if their child begins to stutter.

The Stuttering Foundation commissioned Wirthlin Worldwide to survey 1,000 adults to gauge the extent of public awareness about stuttering.

The survey results indicated that as many as 90 percent of adults may inadvertently react in a manner that could

Both print and broadcast media markets throughout the U.S. picked up on the results of a survey commissioned by The Stuttering Foundation, reaching millions with news of the best way to react to a child who begins to stutter.

frustrate a child who stutters and actually make the problem worse.

"The good news is that wonderful coverage by the news media has helped us make huge strides in educating the parents of young children about stuttering," said Jane Fraser, president of The Stuttering Foundation. "The value of such national exposure is immeasurable in our ongoing efforts at increasing public awareness."

Television broadcasts nationwide aired the story, among them stations in Cincinnati, OH; Harrisburg, PA; Roanoke, VA; Indianapolis, IN; Seattle, WA; Harlingen, TX; Albuquerque, NM; Tampa, FL; Fresno, CA; and Pittsburgh, PA, with a related Web story.

Magazine and other print media, including the nationally syndicated columnist Dr. Robert Wallace of "Tween 12 & 20," also widely ran the story.

## Stuttering: Handedness Survey

by Anne L. Foundas, MD, Associate Professor of Neurology Tulane University Health Sciences Center

The Stuttering Foundation of America assisted with the distribution of a Hand Preference Survey in the summer of 2002. The response was overwhelming and we are still receiving questionnaires from around the world. First, we would like to

thank all of the individuals who participated in this study and the Stuttering Foundation of America for assisting with this project.

Hand preference is perhaps the most blatant behavioral asymmetry observed in humans with 90 percent of the population right-handed and 10 percent left-handed. Most individuals can be easily classified Continued on page 2

1-800-992-9392 www.stutteringhelp.org

# **Delayed Auditory Feedback Most Helpful for Those Who Stutter** with Atypical Auditory Anatomy

(American Academy of Neurology-) Researchers in New Orleans have identified a subset of stutterers that may benefit most from delayed auditory feedback (a technique by which the original acoustic speech signal is artificially modified and

then fed back via headphones). Findings of their study were presented at the American Academy of Neurology annual meeting Honolulu in April.

Delayed auditory feedback (DAF) has been shown to induce

fluency in many individuals who stutter, though not all stutterers experience enhanced fluency by this technique. The primary aim of this study was to learn if there is a relationship between the anatomy of the auditory association cortex (planum temporale) and fluency induced with DAF in adults with persistent developmental stuttering. The planum temporale is a brain structure important in processing auditory information.

A study group of 14 adults with this

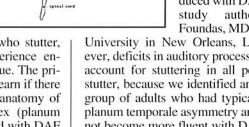
type of stuttering disorder and 14 control subjects read prose passages three times: at baseline, with non-altered feedback, and with DAF. Three measures of fluency were evaluated: stuttering event frequency, severity, and reading time.

"We found a subgroup of adults with atypical rightward planum temporale asymmetry, who were more disfluent at baseline and had fluency induced with DAF," noted study author Anne Foundas, MD, of Tulane

University in New Orleans, LA. "However, deficits in auditory processing cannot account for stuttering in all people who stutter, because we identified another subgroup of adults who had typical leftward planum temporale asymmetry and who did not become more fluent with DAF."

This study was supported by the NIH, the Charles A. Dana Foundation, and the Department of Veterans Affairs South Central MIRECC.

See story on SpeechEasy, page 8.



## **Stuttering Survey**

Continued from page 1

as right- or left-handed based on writing hand, although some people are able to use both hands with nearly equal skill. There are only a few scientific studies that have looked at hand preference in people who stutter, and the results have been conflicting. Some studies have found that there are more left-handers among people who stutter, whereas other studies have not found any difference when people who stutter are compared to people who do not stutter. There is still relatively little known of the neural mechanisms that determine individual hand reference.

Left- or mixed handedness may be a marker of atypical brain organization. Although controversial, there is still interest in the idea that atypical brain organization may predispose individuals to stutter. In addition, stuttering is often modeled as a speech dysfluency associated with aberrant activation of motor systems. Thus, we conducted a survey of hand preference in people who stutter. We were interested in learning whether people who stutter may be be different in the degree and distribution of handedness compared to people who do not stutter. We also asked questions about footedness, which is much less studied than handedness.

#### "Are people who stutter different in the degree and distribution of handedness?"

We are in the process of conducting detailed analyses of the questionnaires that we received. Preliminary results from over 1,000 questionnaires showed that our sample included men (56%) and women (44%). As expected, the ratio of men and women differed when we examined individuals with a more transient pattern of stuttering (male:female ratio 1:2) compared to individuals with persistent developmental stuttering (male:female ratio 3:1). We should complete our detailed analyses in the next three months, and will report on our results in the near future.

Thank you again for your response and assistance with this Hand Preference and Footedness Survey.

Editor's Note: Dr. Foundas was recently awarded the Norman Geschwin Prize in Behavioral Neurology, the most prestigious award in her field, given to academic researchers in the first 10 years of their careers.



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 taxdeductible, subject to limitations under the Code.

# A Salute to "Mister Rogers"

Parents looking for a model of the slow, clear speech best used to talk to children needed to look no further than to "Mister Rogers."

Both the late public television star's gentle, comfortable manner and message of loving yourself and others were superb examples of how to respond to children who stutter, as they were for all children and no few adults.

In working with children with disfluencies, speech-language pathologists as well as The Stuttering Foundation could

point to him and say, "There! Try to talk like Mister Rogers."

For 30 years, Fred Rogers invited children nationwide to be his neighbor as host of the show "Mister Rogers Neighborhood." died of cancer on February 27, 2003 in his Pittsburgh home at the age of 74.

> Rogers produced

the show from 1968-2000, welcoming audiences each day in his signature sneakers and zip-up cardigan. One of his red sweaters hangs in the Smithsonian.

"I think that the most important thing you can do for a child is to offer him

or her yourself," Rogers said.

An ordained Presbyterian minister and a student of early childhood development, he wrote his own songs and did most of the voice and puppetry work.

Lessons on taking turns, sharing, and handling frustration, fear and angeroften part of counseling and treatment for young children who stutter and their families—were staples on the program.

Rogers' show won four Emmy Awards and he was given a George Foster Peabody Award in 1993, "in recognition of 25 years of beautiful days in the neighborhood."



The master of a slow, easy speaking style was a model for us all.

> She is the first woman to receive the award. The Stuttering Foundation of America is

# David Wilkins Has Something to Say to Teens Who Struggle with Stuttering

David Wilkins is a good-looking, outgoing high school senior from South Burlington, Vermont with an irresistible smile. David also happens to stutter.

As the narrator of *Stuttering: Straight Talk for Teens*, a newly released videotape from The Stuttering Foundation, David has a lot to say to other teens who stutter.

"When I began talking, I had a few disfluencies, then I really started stuttering at age three," says David, now 18.

No one else in David's immediate or extended family stutters, so David's speech disorder involved a real learning process for the whole family.

"The hardest thing was that, for awhile, I thought my stuttering would go away overnight. I was like, 'OK, it's time for this to end.'"

David Wilkins

"I was in speech therapy from ages 6-13. The hardest thing was that for awhile, I thought that my stuttering would go away overnight, so in therapy, I was very, very stubborn and did not want to work at all. It was frustrating because I was getting teased. I was like, 'OK, it's time for this to end.' Reading in front of the class was impossible."

Such experiences, and a natural affinity for "being in front of the camera and the center of attention," were some of the reasons David chose to narrate the video. A real desire to help others who stutter definitely influenced his decision.

"I felt pretty strong about doing it, because, with Dr. Guitar, I've been working with a 9-year-old boy who stutters. I've been trying to give back."

The 30-minute video features several teens talking about their stuttering, how they handle social and academic settings,

how they feel about their fluency, where to find help, and what works for them. Speech-language pathologists offer expert information and demonstrate techniques to improve fluency.

Working on the tape was more fun than hard, says David, a veteran of several school stage performances. A stronger sense of self and ease with his own fluency also contributed to his being relaxed on camera. Working with friends (that cute girl in the opening scenes is David's real girlfriend) helped as well.

"Now, I know techniques to manage stutters. All my friends know that I stutter. All the teachers and parents know, and they're understanding. So, I just stay as relaxed as I can be and talk."

"David is a great young man," says Barry Guitar, his former speech therapist. "He's worked hard and has come a long way with his speech, and is really open and comfortable with his stuttering. David loves to help others with their speech, and he felt this video would give him a chance to reach out to those who are still struggling with stuttering."

"Working with Dr. Guitar

and [SFA president]
Jane Fraser was fun.
We went through
eight or nine drafts of
the script, and I made it
my own words."

"In working with David, he was a real natural. We didn't need many takes at all," said director Carroll Guitar. "I think it's great that David is actually stuttering on the video. He knows the tools and techniques to really help his stuttering, and communicates very well, but

by stuttering on the videotape, he really models that it's okay to stutter."

And what advice would he give to oth-

ers, especially young people, who stutter?

"If people are not getting therapy,

I would definitely recommend it," says David, who plans on majoring in speech-language pathology at St. Lawrence University in New York. "If people are struggling with their speech therapy, basically you have to accept yourself as a stutterer, understanding that it won't go away overnight, but it's something that will probably last forever to some degree."

That realization has crossed his mind when he thinks about starting his freshman year in the fall.

"I'm excited about college, but the feeling is there, like what if I get called on in a class of 100 kids and three teachers in a lecture? But, we'll see. I'm psyched for college."

A good student, David received word of his early acceptance to St. Lawrence on the day of filming. What's uppermost on his mind, however?

"I'm going to play soccer there," David says with justifiable pride. "I was a top recruit for the Saints."

Stuttering: Straight Talk for Teens was produced by Barry Guitar, Ph.D., and Carroll Guitar, M.L.S., University of Vermont; in collaboration with Edward G. Conture, Ph.D., Vanderbilt University; Jane Fraser, President, The Stuttering Foundation; Hugo Gregory, Ph.D., Northwestern University; and Peter Ramig, Ph.D., University of

Colorado-Boulder.

For more information on how to order the videotape, call The Stuttering Foundation at 1-800-992-9392.



#### National Stuttering Awareness Week Moves into High Gear

Continued from page 1



advice may actually frustrate a child who stutters.

As many as 20 percent of all children

have disfluencies severe enough to concern their parents. The need is clear for better awareness on how to respond.

"The survey results indicate that it is more important than ever for us to focus our efforts on educating parents of young children about stuttering," said Jane Fraser, Stuttering Foundation president. "Early detection and intervention with young children who stutter can make a real difference. It is crucial that parents become informed, and Nick Brendon's work on behalf of the Foundation has made huge strides in letting people know there is help for this problem."

See survey synopsis on page 8.

# Give to SFA the United Way

If you are a United Way donor, please consider directing your gift to The Stuttering Foundation. Direct designation allows you to specify your gift. Proof of nonprofit status can be supplied to your employer by mail, fax or email.

www.stutteringhelp.org



From left, Diane Hill, M.A., Peter Ramig, Ph.D., Patricia Zebrowski, Ph.D., and Barry Guitar, Ph.D., are all smiles after wrapping up *Effective Counseling in Stuttering Therapy*.

#### Effective Counseling in Stuttering Therapy Updates a Classic

Counseling is an integral part of stuttering treatment, and there are skills speech-language pathologists can learn to become more adept at it. This is the premise behind a major revision of one of SFA's most enduring publications.

Effective Counseling in Stuttering Therapy is far more than a new printing of Counseling Those Who Stutter, first published in 1981. Effective Counseling in Stuttering Therapy reflects recent research, including research into physiological and psychological reactions to anxiety and fear, and current thinking on the positive effects of counseling as a component of stuttering therapy.

The book includes new chapters on Counseling Parents of Children Who Stutter (Diane Hill), Counseling School-Age Children in Group Therapy (Barry Guitar), Understanding and Coping with Emotions: Counseling Teenagers Who Stutter (Patricia Zebrowski), and Counseling Adults in Group Therapy (Peter Ramig). The publication also retains classic chapters by renowned thera-

Effective Counseling in Stuttering Therapy

Therapy

Effective Counseling Gregory, Dean Williams and Eugene Cooper.

"Having edited the original book when counseling or unseling

nal book when counseling therapy was not as widely an accepted part of treament, I was excited to get back

to this book," said Jane Fraser.

For more information, call 1-800-992-9392.

# SFA Booths Are Big Draws at Texas and California Conferences

It's been busy for The Stuttering Foundation on the west side of the Mississippi. While the office staff in Memphis—just barely east of the river—has noticed an increase in requests for SFA materials, "on the road" business has also been brisk.

Late March brought conferences in California and in Texas, as each state's speech-language-hearing association met. The SFA had a booth at each.

"Such gatherings provide an excellent opportunity to stay in touch with professionals in field, to see what their needs are, and how we can best meet them. It's extremely helpful for people to talk to someone about what might work best for their particular clients or how to use a new book or tape in a treatment session,' said SFA's Deborah Squires. "Time and again people say 'thank you for keeping your materials so affordable.' That's always great to hear. It's also wonderful working with a highly experienced clinician like June Campbell; our booth becomes a miniature classroom for therapists who have questions—or an alumni reunion as she greets former students and friends."



Fluency specialist June Haerle-Campbell, CCC-SLP, left, and SFA's Deborah Squires point out new materials to a participant at the California Speech Hearing Association annual conference in Monterey, CA.

Thanks also to speech-language pathologist Jennifer Watson and her graduate students at Texas Christian University and to Tricia Krauss-Lehrman and the NSSLHA members from University of Texas-Dallas who helped staff the SFA booth in Dallas.

## **Annual Audit of Foundation by KPMG**

The annual audit of The Stuttering Foundation financial reports for 2002 was recently completed by the accounting firm of KPMG. Following is a recap of funds and expenditures for the year.

The 3.9% 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	\$668,190	53.1%
Public information and education	297.711	23.7%
Educational Symposia for Professionals		
and research	135.335	10.8%
Maintain Web site and toll-free		
Stuttering Information Hotline	99,976	7.9%
Total for Program Services	\$1,201,038	95.5%
Other expenditures:		
Administration and general	49,345	3.9%
Fund raising expense	7,111	.6%
Total Expenditures	\$1,257,494	100.0%

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.

Normally, www.stutteringhelp.org receives several hundred hits per day, but when stuttering has been in the news lately, daily web traffic can run as high as 1500 hits. Here are some of the typical requests we get from people across the country and around the world.

"If you remember 5 months ago I contacted you to search a help for my stuttering. My name is Burim Ramadani from Macedonia. I want to say to you that now I'm very happy:-) I escaped the fear of my stutter and now I can talk freely. There were two reasons: the first reason is Mr. Peter Toney, the man that you suggested to me to go to, and the second reason is that book

that you mailed to me before [Self-Therapy for the Stutterer]. I don't know how to thank to you, because you did a very, very good thing to me. You are the first person. of course with the help of Mr. Peter Toney, that changed the way of my life.

- I am so glad I found this web site. It has helped give the confidence to talk to my family about getting therapy.
- "I have met a nice woman who stutters and I am interested in learning more about stuttering. How can I be helpful and educated so that I may further develop my relationship with this woman?"
- "Please send information in English and Spanish. The child is 4 and is bilingual.'

Resources for those who stutter can be found free at, www.stutteringhelp.org. Find information in Spanish at SFA's www.tartamudez.org.

- This is a great site and I think you are great for creating this to help people who stutter believe in themselves.
- I just want to thank you for all of your excellent information. Last year and this year I have two very intensive stutterers on my caseload in the public schools. I have used a lot of your materials.
- My daughter's speech has greatly improved. I found your information invaluable!! Thank you for your assistance.
- Well done is what I would like to say to Nicholas Brendon. The Stuttering Foundation is a wonderful non-profit organization that has helped a lot of people including a good friend of mine. Thank you.
- Thank YOU...for having such a great resource and website. It has given me the confidence and drive to address my prob-
- Thank you very much for the book, Self Therapy for the Stutterer. I would like to thank Malcolm Fraser for writing this book. It helps me a lot.

## Public Service Ads in Magazines 2003 a Record Year

This year's National Stuttering Awareness Week got off to a wonderful start early in the year when public service ads (PSAs) featuring Honorary Chair Nicholas Brendon, golfer Ken Venturi, statesman Winston Churchill, and others

appeared March and April issues of many national and regional magazines.

An unprecedented three **PSAs** ran in TIME during March/April! Brendon was also seen in the pages of People Weekly Magazine, Teen People Magazine, Cosmogirl, Redbook in March, April and May, Parenting in both the March and April issues, Seventeen, Good Housekeeping.

Golf. Essence, Black Enterprise, Prevention, Forbes and Forbes FYI, and Kiplinger's all placed the PSA "To Someone Who Stutters, It's Easier Done Than Said" in several issues.

The one-third page ad in the May issue

of Esquire, which features Winston Churchill, generated calls and e-mails from an exciting new audience of readers who had not seen the PSA before.

Some more unusual magazines helping the cause are The Soybean Journal, Beef

> Magazine, Easy Rider, ASPCA Animal Watch, Weight Watchers. and Toastmasters. Each enables SFA to reach a unique readership with help.

American Medical Association publications, AMA News and JAMA also placed recent PSAs, thereby informing the medical community about resources available stuttering from a nonprofit source.

The excellent support of so many magazines brought the total of donated space to a record high over the past twelve months. The Stuttering Foundation extends its heartfelt thanks to the more than 600 magazines that donated space this year.



#### Readers Asked to Participate in Research On Therapy

Have you had counseling or psychotherapy as treatment for a stutter?

Would you like to participate in a study to explore these experiences?

I am currently undertaking a research project as part of my Masters in Counselling Studies at the University of Brighton, England.

As a counselor and someone who stutters, I am interested in improving the experience of counseling and psychotherapy for people who stutter. Consequently I would like to explore how clients who stutter have experienced counseling or psychotherapy when using it to address their stutter:

1) What was helpful?

2) What could have been done differently?

Please email me with your views. On completion, participants will be offered a summary of the research findings.

David Jones jonesd55@ntlworld.com.

#### Workbook

Working with attitudes and emotions in stuttering therapy has proved a popular seminar topic of late, and The School-Age Child Who Stutters: Working

Effectively with Attitudes and

Emotions... a Workbook has become a bestseller among SFA publications.

In January, SLP and workbook co-author Nina Reardon spoke on attitudes and emotions to a packed house in Los Angeles, sponsored by the L.A. School District. The Tacoma, WA, School District sponsored a well-attended presentation by Bill Murphy, M.A., of Purdue University, on dealing with guilt, shame and other emotions.



1-800-992-9392 6 www.stutteringhelp.org

# Stuttering Foundation Launches Spanish Web Site

In an effort to reach more people who stutter, the Foundation launched a Spanish-language Web site, www.tartarmudez.org on March 15.

The Web site contains general information on stuttering for people of all ages as well as a section for pediatricians. All of the Foundation's brochures in Spanish can be downloaded for free from the site in either text or PDF versions.

The site also contains links to features on our English site, such as the list of libraries shelving SFA materials, speechlanguage pathologists who specialize in

Colorful and easy to use, the site was designed and built by Deborah Squires and Jacqui Day, and translated by Marian Prio for The Stuttering Foundation. Information is organized by age group and subject matter, enhanced by lively artwork with an international flair.

The goal was to make the site visually appealing and very user friendly while providing as much information as possible online for the growing number of Spanishspeaking people in the U.S. The Internet also provides a convenient and affordable means of reaching across national borders to Spanish language users around the world, a natural progression as the Foundation already ships materials to more than 60 foreign countries.

#### www.tartamudez.org

"Several years ago I thought it would be a good idea to start working on a Spanish website for our many visitors who feel more at ease in that language," noted Jane Fraser, SFA president. "Our first translation, in the '70s, was If Your Child Stutters: A Guide for Parents. Distribution of all Spanish materials has increased about 20% since last year.

#### To The Pediatrician Now Available in Spanish

The Child Who Stutters: To the Pediatrician is now available in Spanish. El niño que tartamudea: para el pediatra is a translation of the second edition of the -English version. The 16-page booklet contains reproducible pages for parents, and a checklist for referral for the pediatrician.

The Foundation makes these publications available for only \$1.00. The Spanish version may also be downloaded for free at www.tartamudez.org.

"Physicians are often the first professionals to whom parents will turn if they are concerned about their child's stuttering," said SFA president Jane Fraser. "We are very pleased this excellent guide is now available for physicians and their patients who speak Spanish."

#### Spanish Media Targeted for Stuttering Awareness

A Spanish press release was sent to 500 magazines, daily and weekly newspapers.

The gist of the release is to let parents know about the new video tape in Spanish, La tartamudez y su niño: una guia para la familia. It was also the first release that listed the Spanish Web site as a resource for readers.



 Sizio Wéb principal (en inglés) · Catálogo en Enea

Para comunicarse con nesotros Teléfonos: (300) 992-9392 (301) 452-7343 FAC:

FAIC: (901) 452-3931 Dirección postal: 3100 Wallorst Grove Road Suite 803 P.O. Box 11749 Memphis, TN 38111-0749 Esmil: 1

#### Fundación **AMERICANA** DE LA TARTAMUDEZ

#### La Fundación Americana de la Tartamudez

La Stutering Foundation of America (SFA) o Fundación Americana de la Tartarrudez ofece información, sencicios y apoyo a las personas que tartarrudean y sus familiares a la sez que ayuda a franciar investigaciones sobre las causas de los que tartarrudean y los profesionales que los fratara y ofece programas educativos para las profesionales. La 95 Año 43 mayor y más antiquas parada a la prevención del tartarrudeo y mejoramento de los métodos paras us tratamento. Legarno a más de un millón de personas al año y esperamos serie (st.).

- Sabia usted que...
- Cómo hablarle al niño...
- Folletos

- Si usted cree que su niño tartamudea (fexto) (PDF)

  B niño que tartamudea en la escuela (fexto) (PDF)

  B uso del telébro (fexto) (PDF)

  Cómo reaccionar cuando se habla con alguien que tartamudea (fexto) (PDF)

#### Inicio Quienes Somos

- Ventas en línea
- Personajes famosos con tartamudez



- Enlaces

Sitio Web principal, en inglés, de la Stuttering Foundation of America, con información adicional. Otros sitios relacionados con la tartamudez.

 Linea telefónica gratuita

La Stuttering Foundation of America mantiene una finea telefonica gratuita (sin cargos de larga distancia dentro di los Estados huldos); (300) 902-9392. Con una llamada (e inglés), podrá obtener folletos gratis y listas de foniatras especializados en la tartamadez.



Dr. Fred Murray atop the Morro Castle Lighthouse in the Havana Harbor in Cuba. In January, Murray once again visited the city with Spanish language materials from The Foundation to share with the education department. The Foundation has also granted the Cuban agency permission to reproduce the materials.

The lighthouse overlooking the entrance to Havana Harbor is Dr. Fred Murray's only memory of Cuba the first time he sailed past it in 1932 at age 7. This trip, he got to see it from the top.

Murray was in Havana for four days in late January, a follow-up trip to one he made last year, taking a number of Spanish-language materials from The Foundation and meeting with officials in an effort to provide the Cuban people with information on stuttering.

"This time I went down with more things than I had before," Murray said. "I was determined to find out what happened, so I went right away to the department of special education. They were absolutely thrilled with what I had."

During Murray's first visit back to Cuba in 2002, he met with program director Tatiana Chkout of the Dirección de Educación de la Republica de Cuba. The Stuttering Foundation has since granted permission for the agency to reproduce the materials themselves, thereby making them more available.

"Tatiana was just ecstatic about the materials," Murray said of a recent telephone conversation he had with the director. "She said, 'you can't imagineit's just like having diamonds."

# Entrepreneur Cites SFA for Effective Ad

Entrepreneur Magazine doesn't usually focus on nonprofit organizations, but the April 2003 issue singles us out!

A marketing column by Jerry Fisher entitled "Legends for Hire" gives The Stuttering Foundation top marks for our public service ad featuring Winston Churchill. Following is an excerpt:

"It's important to do your legend shopping wisely, realizing that some celebrity/product marriages work better than others do... an A+ example of the melding of a legendary image with an advertising message is captured in the ad shown here. Created for the Stuttering Foundation of America, the ad depicts the most well-spoken and famous British statesman of all time, Winston Churchill, along with this headline: "The voice of freedom never faltered, even though it stuttered." One can't imagine a more inspiring person and message for someone who's self-conscious about such an impediment."

The Churchill public service ad is one of our most enduring ads, and a favorite of many of the publications who run our PSAs. But Mr. Fisher didn't mention the best part—all of our PSAs run for free. So every time you see that Winston Churchill ad, or any of our other PSAs featuring well-known people who stutter, say a 'thank you' to the magazine, which supports our public awareness campaign by donating the advertising space.

## We're Living Online, Say SFA Web Stats

Interpreting the Mileage Signs on the Information Highway

We're a society that lives increasingly online, and judging by The Foundation's own Web statistics, that holds true for other countries. Moreover, we're logging on week-days—especially on Monday—to do

our serious surfing, and saving our **weekends** for other pursuits. That would coincide with statistics that indicate we're accessing the 'net mostly at **work**.

While these statements are based solely on data compiled by the SFA about traffic on its own Web site, the numbers are both fun and revealing.

A look at one month's Web use provides an interesting case in point. In March alone, there were 512,705 hits on our main site at www.stutteringhelp.org. But Websavvy readers cast a critical eye on raw hit data. (It gives little indication of who actually checked out the site, and to what extent. To drive up your own hits make your site your home page—that's all it takes.) Instead, we'll look at unique users, which numbered 16,260 in March.

We know our Web site is far busier just after a national news story on stuttering, proof of the power of the press. But even after slow news days, March's client sessions were as high as 1,100 per day, peaking at over 1,800 per day—an average of 1,315 user sessions per day.

So where are people going on this information highway?

On our site, to basic information and resources about stuttering, above all. If You Think Your Child is Stuttering is the most popular "roadside" stop. closely followed by resources (such as libraries with free materials), brochures that can be downloaded for free, and referrals for therapists specializing in stuttering treatment. Information on electronic

devices to aid those who stutter and on insurance reimbursement information also rank high. Over 400 users downloaded The Child Who Stutters: To the Pediatrician and 300 downloaded the newsletter.

Of course, examining one month's SFA Web statistics is not truly indicative of how we spend our online time. It can, however, tell us how effective our Web site is in helping those who stutter and give us **crucial** data to continuously improve our site.

And sometimes, just counting the mile markers along the way is **fun**.

## Sometimes I Just Stutter now in Japanese and Afrikaans

Sometimes I Just Stutter, the book for children ages 7-12 who stutter, is now available to children in Japan and in South Africa in their own languages.

Published by The Stuttering Foundation in 1999, the popular book was originally written in Dutch by author Eelco de Geus, a therapist in the Netherlands who works with young children and adolescents who stutter. The book has information about stuttering, and about the feelings that children may associate with stuttering. There are also stories by and about

other children who stutter, and sample letters that children may copy and send to family members to help tell them about how they wish to be treated when they stutter. Sometimes I Just Stutter was translated into English by Elisabeth Versttegh-Vermeij. It has since been translated into several other lan-

guages.

イルコ・テ・ギース さく

おだに みつる やく

資訊存得的平引主義

全国西語障害児をもつ親の会

Japanese translator Mitsuru Odani sent copies to the Foundation in April from Tokyo with these comments:

"I had the permission of the translation of *Sometimes I Just Stutter* from you last year. This month it was finally published by the Japanese edition. I deliver some new books to you at once with joy. It is happiness if you put these on your desk. Thanks are said from the children worried about stuttering in Japan."

The Afrikaans version also arrived recently, with a lovely letter from translator Ursula Zsilavecz, a lecturer in the Department of Communication Pathology Speech, Voice and Hearing Clinic at the University of Pretoria in

South Africa

"Thank you once again for granting permission to translate the book into Afrikaans.

Now it is available to many other fellow citizens in our country and can be of use to teachers and paren ents alike."

For a Japanese version, contact

Mitsuru at 1-25-5 hanekami, Hamura-shi, 205-0016 Tokyo Japan. For a book in Afrikaans, contact Ursula at University of Pretoria, Pretoria 0002, Republic of South Africa, www.up.ac.za



www.stutteringhelp.org

## SpeechEasy Device Stirs Interest, Raises Questions

Peter Ramig, Ph.D., ASHA board recognized fluency specialist, calls himself a "traditional speech-language pathologist." Unlike many of his colleagues, however, he's willing to sell, and to talk openly about, the SpeechEasy device, an electronic fluency aid that's been making headline news and raising questions.

The SpeechEasy was developed by an East Carolina University (ECU) research team led by Michael Rastatter, Ph.D., and marketed by Janus Development Group, Inc., a spin-off company. It uses both delayed auditory feedback (DAF) and frequency altered feedback (FAF). Janus claims that "stuttering is reduced in 80-90% of the stuttering population." The company has sold more than 1000 devices since June 2001, and is currently fitting about 100 a month.

Does it work? "The company openly states that this device works for some people and it does not work for others," says Ramig. "Initially, I was as negative about it as a lot of other people have been, but I thought, 'how can I give advice about it when I don't know anything about it?' So I decided I needed to learn more in order to better answer the scores of inquiries I was receiving. I then decided to accept Janus' development invitation to go through the training. In doing so, I invited three of my colleagues, all SLPs who stutter, to join me. The four of us went into the training with more skepticism than optimism, but we vowed to keep an open mind. By the end we felt more optimistic about its feasibility in helping some, not all, persons who stutter. As clinicians we all know there are some people out there who have been through stuttering therapy, but have not benefited to the degree they wished to. If SpeechEasy works for only a few of those people, then it's well worth it."

It's the combination of DAF and FAF that appear to make this product more effective than others on the market, say its developers.

"Just the DAF has often not worked long-term," notes Ramig, who says that the basic technology and DAF devices have been around for about 40 years.

What does it cost? There are three models of the SpeechEasy. The two most popular cost \$4,500 and \$4,900 for the advanced models. In most cases, insurance will not pay for the device.

Janus will refund 90% of the purchase price of the device if it is returned undamaged within 30 days of the date of purchase. The warranty does not include fitting fees, which typically run \$300-\$500 for about three hours initially, with a follow-up visit if needed.

Fitting includes a hearing evaluation, stuttering evaluation, device demonstration and counseling, ear mold impressions, and custom-fitting and calibration.

"If the device does not substantially help the client in the initial fitting session, it should not be sold to them," says Ramig. "However, I would prefer to see Janus offer a 60-90 day trial period to better determine its helpfulness."

The long-term effectiveness of the SpeechEasy seems to be the major question. Rastatter says the university has completed a one-year study of the long-range effectiveness of the device and fluency rate of users, originally due out November 2002. Results have not been published, however, "These data show that an adaptation effect does not occur as no significant differences existed in the amount of stuttering between the initial fitting date and the post testing date," Rastatter wrote in an email response.

"To me, it is another tool in our arsenal that we can draw from."

Peter Ramig

"There is not a single, peer-reviewed, published clinical research study demonstrating that this device produces sustained and satisfactory improvements in fluency—and for what percentage and age range of people who stutter—let alone that it produces benefits that are retained following extended use," wrote California researchers Roger and Janis Ingham in a letter to the ASHA Leader (April 15, 2003.)

"There need to be outside persons who do a research study," Ramig agrees, "not just the company." Who may benefit? A person with some therapy is more likely to be a good candidate for the device, someone who has learned to "turn on" their voice. If you block silently, the machine doesn't work. Part of the fitting session is devoted to strategies to initiate voicing.

The prime candidate, Ramig says, is one such as a recent client of his—over 60 years old, someone who has stuttered all his life, and has had some therapy with little improvement. He lives in an outlying area where there are few services.

"When we fit him, there was marked improvement, although it didn't eliminate his stutter. Still, he insisted on purchasing the SpeechEasy because of the improvement," Ramig says.

"To me it is another tool in our arsenal that we can draw from" Ramig sums up. "It's not something that I'm pushing as the answer to all stuttering problems. I still believe wholeheartedly in the positive efficacy of combining traditional fluency shaping and stuttering modification for most people who stutter. But it's not something that I'm going to withhold if it appears to help the person who has not been helped by those methods."

Editor's Note: Information about a various electronic devices (some of which are more moderately priced), including SpeechEasy, is available on our Web site, www.stutteringhelp.org. The Stuttering Foundation does not warrant the efficacy of these devices nor guarantee their treatment in any way. The Web page and this article are for information only, and do not constitute an endorsement.

# Synopsis of the Survey on Parental Reaction to a Child Who Stutters

(A national survey of 1002 respondents conducted by Wirthlin Worldwide and The Stuttering Foundation, Plus or minus 3% error rate.)

## How Should Parents React to a Child Who Begins to Stutter?

1. Ignore the problem

6% Yes

94% No

2. Change the child's environment

21% Yes

72% No

7% Don't know/refused

3. Seek professional help

84% Y

14% No

1% Don't know/refused

4. Tell the child, "slow down/relax"

88% Yes

10% No

2% Don't know/refused

5. Correct the child and finish sentences

33% Yes

65% No

2% Don't know/refused

■ What Should Parents Really Do?

- Remain calm if you hear your child stutter.
- 2. Give the child your attention and listen carefully, allowing the child to complete his sentence without interruption.
- Talk in a slow, relaxed way yourself; this will be more effective than any criticism or advice to 'try it again slowly.'
   Convey that you are listening to what your child says, not how she says it.

Demographics on respondents:

- 48% are male; 52% female
- Age ranges from 18-75 and older, with 52 % falling between the prime parenting ages of 30-54 years old; and 55% are married
- 76% of respondents have 1 or more children
- 61% have completed some education past high school
- 62% are employed full- or part-time
- 85 % are registered to vote
- Race:10% Hispanic; 73% White;
   12% African-American; 4% Other mixed ethnic origin.
- Geographically diverse (9-point Geo-codes, from New England to the Pacific)

#### 9

## **News Shorts**

#### Libraries Say Thanks

The following letter is typical of many we receive in response to our campaign to stock public libraries with materials. For a list that do, click on Resources on our Web site at www.stutteringhelp.org.

"We so appreciate your generosity in allowing us to choose books from your organization, free of charge. Added to our circulating collection are: Stuttering and the Preschool Child:Help for Families (video), Stuttering and Your Child: A Video for Parents, and Self-Therapy for the Stutterer, 10th edition. Clearly, the availability of these resources will help many people improve their lives."

Penny Reeves, Executive Director Lexington Public Library

# Workshop on Fluency in the Preschool Population



Speech-language pathologist Phillip Schneider gave a workshop on fluency issues related to the preschool and 0-3-year-old population on April 29. The seminar was sponsored

by a special education preschool and Early Intervention Center in Rockland County, New York. The Stuttering Foundation provided CEUs for the event.

#### Self-Therapy in Thai

■ Self-Therapy for the Stutterer is being translated into Thai by Chakrapan Sutatvoravut, who writes that the book has helped him with his stuttering.

#### QVC Channel Airs Public Service Message

■ Santa wasn't the only one delivering gifts on Christmas Eve. Apparently, a lot of late-night shoppers were tuned in to QVC, judging by the number of phone calls SFA received after the shopping channel aired our public service announcement during its holiday broadcast. Thanks, QVC, for assisting us in getting out the word about stuttering and what can be done to help.

#### Handedness Across the Water

"Hi Friends of the SFA, I read an article on your web site con-

cerning the above research project on the handedness and footedness of people who stutter. I discussed it with many members of SCAC, a support group movement for persons who stutter in Cameroon, and many of them are ready and willing to take part in the said research project. If you think that you can collect some data from this our part of the world you should feel free to contact us." Joseph Lukong,

Republic of Cameroon

#### Go Ca I ling you

#### Going Flying? Catch a Star!

If you're going flying anytime in June, you may have the chance to catch a star a television star that is. SFA

spokesperson Nicholas Brendon's interview with CNN News will be airing on the

in-flight programming on Continental Airlines flights throughout the month, about 5,000 flights. As we went to press, 12 people had donated to the SFA through the Nick Appreciation Day fundraiser on Brendon's Web site!

#### NSSLHA Chapters at Two Universities Donate to Stuttering Foundation

■ A big thank you to the National Student Speech, Language, and Hearing Association chapters at Kansas University and Eastern W a s h i n g t o n University. Both chapters sent donations to the Foundation to help support our programs.

Eastern Washington's chapter made its donation in honor of Dr. Dorvan Breitenfeldt for his work, and asked that the money be used to pay for training programs for speech-language pathologists—an appropriate choice!



#### India Web Site

■ Dr. Sajiv Adlakha, a therapist with the Adlakha Speech & Hearing Clinic in New Delhi, has launched a Web site with information on stuttering as well as other speech disorders. The English-language site is www.speechtherapyindia.org.

# In Memoriam: Brian Scott Keneman



Brian Scott Keneman, 30, passed away Feb. 4 in his home in Trenton, NJ. The family asked that those closest to the young man remember him with a donation to The

Stuttering Foundation in lieu of flowers.

Through this generous gesture

Through this generous gesture, Brian is still touching others' lives in the positive way he did throughout his life. In addition to donations, the Foundation received a tremendous outpouring of letters from Brian's coworkers at UPS, his family and extensive circle of friends. Without exception, they speak of the young man's generosity, loving kindness, quick wit, free spirit, and of his skill as an artist in several media—paint, music and interior design.

"While Brian's death was tragic and sudden, his family wished to donate gifts to a charity that Brian would have thought to be genuinely helping others," wrote SLP Caroline Harbat. "Brian would be gratified to know that he is helping other adults and children who stutter, whether it be through research, prevention, or therapy. The Stuttering Foundation is an excellent resource for individuals who stutter, their family members, and therapists like myself. Brian will continue to inspire others who stutter, and to those who interact with individuals who stutter. May he never be forgotten."

To the family and friends of Brian Scott Keneman, The Stuttering Foundation says "Thank you."

# NEWSBRIEFS

- 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 6-7, 2003 in Philadelphia, PA. For an application, contact The Stuttering Foundation at 1-800-992-9392 or download it directly at www.stutteringhelp.org.
- The Stuttering Foundation two-week Workshop for Specialists will be held at the University of Iowa, Iowa City, IA, June 23-July 3, 2003, directed by Patricia Zebrowski, Ph.D., with Toni Cilek, M.A. This unique workshop brings together speech-language pathologists from all over the world. 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.

   The Stuttering Foundation Eastern Workshop, Diagnosis and Treatment of Children Who Stutter: Practical Strategies, directed by Dr. Susan Dietrich and Dr. Sheryl Gottwald will be

held at Boston University, June 18-22, 2003.

- The Stuttering Foundation Western Workshop, Diagnosis and Treatment of Children who Stutter: Practical Strategies, directed by Susan Hamilton, M.A., Jennifer Watson, Ph.D., and with David Prins, Ph.D., will be held at the University of Washington, Seattle, June 25-29, 2003.
- The Stuttering Foundation Southern Workshop, Diagnosis and Treatment of Children Who Stutter: Practical Strategies, directed by Dr. Lisa Scott Trautman and Kristin Chmela, M.A., will be held at The Florida State University, June 2004.
- The 4th World Congress on Fluency Disorders will be held August 11-15, 2003 in Montreal, Quebec, Canada. For more information contact Dr. Rosalee Shenker at mirs@musica.mcgill.ca or Lisa Avery at avery1@interchange.ubc.ca.
- Speak Easy Symposium XXII, May 2-4, 2003, A Conference for People Who Stutter, will be held at the Saddle Brook Holiday Inn, in Saddle Brook, NJ. For more information, call Bob or Antoinette Gathman at 201-262-0895 or email: bobantoinette@worldnet.att.net.
- The Sixth Annual Convention of FRIENDS: The Association of Young People Who Stutter. August 7-9, 2003 in Secaucus, New Jersey. For more information, call toll-free 866-866-8335 or email lcaggiano@aol.com or jtahlbach@aol.com.
- CAPS (Canadian Association of People Who Stutter) Conference, Toronto, Ontario, August 6-10, 2003. Download information at www.stutter.ca/caps2003; email: caps@stutter.ca; or call toll-free 1-888-STUTTER.
- The NSA Convention will be held in June in Nashville, TN. For more information, call 1-800-364-1677, visit www.nsastutter.org, or email nsastutter@aol.com.
- Joe Donaher has started a LISTSERV for doctoral students specializing in stuttering. The intent of this list is to serve as an open foru. Membership is limited to doctoral students only. To subscribe, please send the following message to listserv@listserv.temple.edu: subscribe stutterdoc firstname lastname or contact Joe Donaher at 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, 77, Sant Nagar, East of Kailash, New Dehli-110065, India, or call at 011-91-628-8636, e-mail: adlakhas@hotmail.com. The publications are also available at www.speechthera-pyindia.org. Those interested in joining a fluency and public speaking skills group should also contact Dr. Adlakha.

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

- Stuttering Therapy: Rationale and Procedures, (2002) by Hugo H. Gregory, June H. Campbell, Diane G. Hill, and Carolyn B. Gregory. Available from Allyn and Bacon at www.ablongman.com.
- Les begaiements: Histoire, psychologie, evaluation, varietes, traitements, (2001) by Anne Van Hout and Françoise 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.
- 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.
- 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, 906-942-7879.
- Living With Stuttering by Kenneth St. Louis, Ph.D. Available from Populore Publishing Company, P.O. Box 4382, Morgantown, WV 26504, 304-599-3830.
- Jason's Secret by Ellen Marie Silverman, Ph.D. Published by 1st Books Library. www.1stbooks.com.
- Stuttering: Its Nature, Diagnosis, and Treatment, by Edward G. Conture, Ph.D., published by Allyn & Bacon, Needham Heights, MA. (781) 433-8410.
- Stuttering: An Integrated Approach to Its Nature and Treatment by Barry Guitar, Ph.D., published by Lippincott, Williams, and Wilkins, Baltimore, MD. (800) 638-3030.
- Successful Stuttering Management Program, Second Edition, by Dorvan Breitenfeldt, Ph.D., published by EWU Press, Cheney, WA, (509) 235-6453.

- Synergistic Stuttering Therapy: A Holistic Approach by Sister Charleen Bloom and Donna K. Cooperman. Published by Butterworth Heineman, Woburn, MA.
- Stuttering Intervention: A Collaborative Journey to Fluency Freedom by David Allen Shapiro, published by Pro-Ed, Austin, Texas.
- *Tongue Wars*, by William H. Perkins, Ph.D., Athens Press, Los Angeles, CA, 800-364-1677.
- The Bob Love Story: If It's Gonna Be, It's Up to Me, by Bob Love with Mel Watkins, available through bookstores or call NTC Contemporary Publishing Group, 1-800-323-4900.
- Paroles de parents by Anne-Marie Simon, L'Ortho-Edition, 76, rue Jean Jaures, 62330 Isbergues, France.
- Clinical Decision Making in the Diagnosis and Treatment of Fluency Disorders by Walter H. Manning, Ph.D., published by Singular/Thomson Learning.
- Nature and Treatment of Stuttering: New Directions by Richard F. Curlee, Ph.D. and Gerald M. Siegel, Ph.D., published by Allyn and Bacon, Needham Heights, MA.
- The Classroom Teacher's Inclusion Handbook by Jerome C. Yanoff, Arthur Coyle Press, Chicago, IL.
- Straight Talk on Stuttering, Information, Encouragement, and Counsel for Stutterers, Caregivers, and Speech-Language Clinicians by Lloyd M. Hulit, Ph.D. The publisher is Charles C. Thomas, Springfield, IL.
- Stuttering: A Life Bound Up in Words by Marty Jezer. Published by Basic Books, 1997.
- You Will Dream New Dreams: Inspiring Personal Storiesby Parents of Children With Disabilities by Stanley D. Klein, Ph.D., Published by Kensington Books, New York, NY, 1-800-221-2647
- Stuttering and Science by William H. Perkins, Ph.D. and published by Singular Publishing Group, Inc., in San Diego, CA.
- Elements of Stuttering by Courtney Stromsta, Ph.D. Available from Stuttering Foundation, 800-002, 9392
- Stuttering: A Search for A Cause and a Cure by Oliver Bloodstein, Ph.D. It is published by Allyn & Bacon, Needham, MA.
- Unforgettable Characters I Have Known by Bill Lynde. Published by BookPartners in Wilsonville, OR, 503-682-9821 or 800-895-7323.
- Dead Languages by David Shields. Available now in paperback edition by Graywolf Press, Saint Paul, MN, www.graywolfpress.org or call 612-641-0077.

We are indebted to all donors whose continuing support enables us to carry out our vital work on behalf of those who stutter.



A Nonprofit Organization Since 1947 — Helping Those Who Stutter 3100 Walnut Grove Road, Suite 603 P.O. Box 11749 • Memphis, TN 38111-0749

1-800-992-9392 • 1-800-967-7700

www.stutteringhelp.org www.tartamudez.org info@stutteringhelp.org